Children and
Family Series

When Kids Belong

Supporting Children with Complex Needs — At Home and In the Community

L'Institut Roeher Institute

WHEN KIDS BELONG:

SUPPORTING CHILDREN WITH COMPLEX MEDICAL NEEDS AT HOME AND IN THE COMMUNITY

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L'Institut Roeher Institute, Kinsmen Building, York University
4700 Keele Street, North York, Ontario, Canada M3J 1P3
Tel.: (416) 661-9611
Fax: (416) 661-5701
TDD: (416) 661-2023

Institute President
Cameron Crawford

Principal Researchers
Daune MacGregor, MD
Marcia Rioux, PhD
Yves Talbot, MD

Project Coordinator and Senior Consultant
Michael Bach

Researchers
Leela Viswanathan
Mary Bunch
Michael Bach

Editing and Layout
is five Communications

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About

L'Institut ROEHER *Institute*

Canada's National Institute for the
Study of Public Policy Affecting
Persons with Intellectual
and Other Disabilities

L'INSTITUT ROEHER INSTITUTE IS CANADA'S POLICY RESEARCH ORGANIZATION promoting the equality, participation and self-determination of people with intellectual and other disabilities, by examining the causes of marginalization and by providing research, information and social development opportunities.

To fulfill this mandate, The Institute is engaged in many activities: research and public policy analysis; publishing; information gathering and dissemination; and training, education and leadership development.

The Institute acts as a centre for the development and exchange of ideas, all of which are founded on a new way of looking at disability in the context of a strong civil society. It critically examines issues related to the well-being and human rights of persons with disabilities. Based on its examination of these issues, The Institute raises awareness about the barriers that affect people's full participation in society and that prevent them from exercising their rights. The Institute also presents policy and program alternatives.

For more information about The Roeher Institute please contact us at:

Kinsmen Building
York University
4700 Keele St.
Toronto, ON
Canada M3J 1P3
Tel: (416) 661-9611
Fax: (416) 661-5701
TYY: (416) 661-2023
1-800-856-2207
e-mail: info@roeher.ca
http://indie.ca/roeher

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FOREWORD

Children deserve to be loved and nurtured at home, with their family. They deserve the opportunity to develop their dreams, and to take part with neighbourhood friends in learning and play. They deserve to be safe and secure, and to grow healthy, strong and confident. Every family wants at least this much for their children.

But some children's dreams and everyday activities are interrupted. The health and security that most children take for granted are precious goals for others. And when the health of the child is compromised, the family can be thrown into anxiety and chaos.

Some children have complex medical needs. Some are born this way, while others are injured or acquire diseases early in life that may be with them for years if not for a lifetime. Some children have needs that are more or less constant, while others have health-related needs that are episodic and unpredictable. This is particularly likely to be the case when children have disabilities.

For parents, this can mean long hours of waiting in emergency wards, endless visits to doctors, time and energy diverted from other family members, life on the job made tenuous, ordinary routines frequently broken and financial hardship. For the child this can mean insecurity, fear and loneliness, especially when the care needed is not available in the community, but only in the hospital or some other clinical setting.

When Kids Belong describes the planning supports that children and their families need so they can remain in their communities, so routines can be livable, so a measure of security can be assumed and so ordinary development can take its course. The report draws from an extensive literature review, focus groups with physicians, other health professionals, hospital-based social workers and perhaps most importantly, parents. It maps the challenges and obstacles that parents face in supporting their children in the community while attending to important health issues. It also sheds light on the frustrations and concerns of health-related professionals in their efforts to put their expertise at the service of children and families in the community.

But the report moves beyond the chronicling of problems and points to concrete steps that can be taken to put in place the kind of planning support that is needed if the health of children is to be optimized without compromising other important ends, like friendships, going to school, play, and time together with other family members

I would like to thank the family members, paediatricians, family physicians, and health care coordinators who took part in the research for the invaluable wealth of experience and knowledge they brought to the table. Particular thanks are due to Drs. Daune MacGregor, Marcia Rioux, and Yves Talbot for their vital guidance, energy and

leadership on this project, and to Michael Bach for project development and coordination. Thanks are also due to Mary Bunch, Leela Viswanathan, Michelle Connel, and Michael Bach for drafting the report in collaboration with the research team.

It is our sincerest hope that this report will make a positive contribution to children living with complex medical needs and their families. We hope and trust that professionals will find it a valuable resource to assist them in their efforts to enable children who sometimes feel quite vulnerable to thrive with their families in their communities.

Cameron Crawford
President

INTRODUCTION

With current deinstitutionalization policy, increased medical technology and expansion of human rights to include social rights, children with disabilities and/or complex medical needs are more likely to survive, and to remain within the family for most of their childhood and early adult life. Views that children and youth with complex medical needs can live only in long-term care facilities; likely have a short life with little quality; and are burdens on their families and society are gradually changing. Families, health professionals, educators and others are beginning to recognize that like other children, those with complex medical needs deserve a childhood with dignity and love at home with their family and in their community. Being nurtured in their community by parents and through relationships with health, education and other social services is seen as essential to their well being. It is understood that their well-being depends on others believing in their fundamental value, potential, and in their future.

There are many challenges, however, in creating service and support systems that enable children with complex medical needs to live at home, to go to a child care centre, to attend school, and to participate in their community. Their needs for technological support and intensive health care services on a regular basis, as well as the demands on their parents, can be daunting. Children and families need access to a range of health and social supports. Yet the provision of effective individual planning and coordination of services for children with disabilities and their families has not been adequately addressed by the current system of health care and social services.

The primary and acute health care systems have not included in their design the means to support and enable community living for children with intellectual disabilities who have medically complex needs. In some cases, funding and service delivery arrangements have provided incentives for institutionalization and facility-based responses. Deinstitutionalization and community living efforts are unlikely to be successful unless there is a reorientation and redesign of the health care and social support systems. The ongoing medical and social support concerns of children with complex health needs living in the community or moving from long-term care facilities to the community need to be taken into account.

Challenges arise not so much from the nature of children's needs and the intensity of support both they and their parents require, but often because children with complex medical needs do not fit neatly into the services of any one system — whether health care, education, or social services. Yet many successful examples do exist where families, service systems and communities link the resources needed in unique and supportive ways. These examples provide lessons on how to reorganize resources and supports so that children and families can be more fully supported at home and included in their communities.

Children who have complex medical needs, in addition to any other disabilities are the focus of this report. However, it is important to make a distinction between the health-related, and the disability- and community-related needs faced by children and families. Children with complex health needs often interact with the health system much

more often and more regularly than other children with and without disabilities. Consequently, health planning may play a larger part in ensuring their well-being, their inclusion in community activities, living at home, going to school, and being involved in leisure and recreational activities with other children.

It should be noted that while the language used in this report emphasizes *health* planning, it does so in the context of children who have extensive health concerns. A number of recent studies have shown that parents of children with complex medical needs, as well as parents of children with disabilities in general often need general planning support. Such support includes planning for social, education, leisure and other community activities, as well as medical activities. However, because of the extensive contact children with complex medical needs have with health professionals and health organizations, such support has often been provided by, and through the health systems and is referred to as health planning.

The term *health planning* has been used in this report as a strategy to legitimize the planning process in the eyes of the health community, as part of the transition from health institutions to community living for children with complex medical needs. The intention is not to medicalize the support needs of children and families. Rather, the intention is to begin to move the planning process for both medical and other support needs outside of the health systems, so that these processes are more accountable to families. In the end, it is not *health planning* that occurs, but planning support that accounts for medical as well as other supports.

This report synthesizes a number of recent research projects at the Roeher Institute that have examined issues faced by children with complex medical needs and their families, as outlined in the Methodology in Section I.

Section II outlines some of the major social and policy trends that affect children with complex medical needs and their families. These include: demographic shifts; changing definitions of health; shifting assumptions about disability; government commitment to deinstitutionalization; shifts in the philosophy of care; health restructuring and an emerging national vision for children with complex medical needs and their families. This sets the backdrop for issues that arise for families with respect to accessing the supports they need, and the issues faced by communities in developing the capacities to meet those needs. Next, drawing on research in Canada and elsewhere, the broad policy trends in meeting the range of needs of children with complex health needs and their families are reviewed.

Issues specific to the process of health planning for children with complex medical needs and their families are addressed in Section III. The experiences and perspectives of families and health professionals are explored with respect to obtaining planning support, defining needs and making diagnoses, making decisions about appropriate supports, services, and treatments, arranging for the delivery of needed supports, services and treatments, and ensuring ongoing planning support and coordination.

Section IV reviews the models for health planning that are currently being used for this group, outlining the models and the corresponding issues people face in the health care system. Existing models are critiqued to draw out their benefits, as well as their limitations.

The final section proposes an alternative supported health planning model, which draws on the benefits and addresses the limitations of other models, and is based on clear aims and principles. An action plan for supported health planning is suggested.

I. METHODOLOGY

This report combines the findings of a number of recent reports by the Roeher Institute that explore issues pertaining to children with complex medical needs and their families. The research employed three main methodological tools: reviews of the literature; qualitative data collection and analysis and analysis and synthesis of qualitative data and the literature.

1. Literature reviews

Literature is drawn from the *Research Review on Community-Based Supports for Children With Complex Medical Needs and Their Families*commissioned by the Office of Integrated Services for Children and the Ontario Ministry of Community and Social Services/Ministry of Health. The research involved a review of literature examining demographic, ideological and policy trends and shifts with respect to health and other supports for children with complex medical needs and their families. It also explored literature outlining some of the issues faced by families and by communities in supporting children with such needs. It further examined strategies identified in the literature for developing community capacity to support children with complex medical needs.

Literature was also drawn from the *Health Planning Innovations Project Background Report: Developing A Model For Health Planning For People with Disabilities Including Those With Complex Medical Needs*. This review examined current trends and shifts, as well as issues identified in the literature which related to health planning in areas such as obtaining planning support, defining needs and making diagnoses, decision making, service arrangement and delivery and ongoing planning support and coordination. It also explored existing models of health planning.

2. Qualitative Research

Informant interviews and focus groups were conducted as a part of the *Health Planning Innovations Project Background Report*. Informant interviews focussed on the development of a model of health planning and coordination with discharge planners, public health nurses, and hospital-based social workers. In addition, five focus groups were held which included families with an adult member with an intellectual disability, several of whom were additionally labelled as having a psychiatric disability, health care coordinators[1], paediatricians, and general practitioners/family physicians. The participants in the interviews and focus groups identified issues that inform the development of the health planning and coordination model. The questions that guided the focus group discussions are provided in Appendix B at the end of this report.[2]

3. Analysis of literature and qualitative data: Developing the model

The final section of this report that outlines The Supported Health Planning Model was drawn from *Supported Health Planning: A Model To Assist People With Disabilities And Complex Medical Needs, And Their Families, In Planning For Community Inclusion*. In devel-

oping the model, key issues in the design and delivery of health planning that were identified by the interview informants, focus groups participants, and in the literature reviewed were analyzed. Based on this analysis, elements of a model for health planning and coordination were identified and a model developed.

[1] Health care coordinators represent a variety of group homes and health care support agencies in Toronto. In addition to coordinating personal health care support for their clients, they provide professional training and instruction on the provision of health care support.

[2] The focus groups were held in Toronto. Participants came from the Greater Toronto Area as well as from other regions in southern Ontario. The focus groups varied in size from seven to ten participants, not including the two researchers.

II.
SOCIAL AND POLICY CONTEXT

1. Current Trends

Demographic Shifts

Research based on the 1996-97 National Population Health Survey (NPHS) has found that there are nearly 565,000 children and youth between birth and 19 years of age (living in households) who had disabilities when the survey was conducted — 7.7% of all children living in households (CICH, 2000: 9-1). The general health status of children with disabilities in the 4 to 14 years of age group is excellent or very good for only 58%, compared with 87% among other children this age. Based on earlier information it is known that, among children with disabilities, 15% (more than 80,000 children) have a moderate or severe level of disability (CICH, 1994, 8-3). More than 200,000 children from birth to 15 years have long-term health problems or chronic conditions aside from asthma, allergies and bronchitis, and more than 160,000 are limited or prevented from participating in school, play or other typical activities because of long-term conditions. Nearly 20,000 had non-reimbursed expenses for health and medical services in 1991, and nearly 80,000 had non-reimbursed expenses for prescription and non-prescription drugs taken regularly because of a long-term condition (Statistics Canada, 1994: Table 5). A recent survey by the Ontario Ministry of Health concerning children registered with and/or supported by Community Care Access Centres (CCACs) in the province indicate that 1,700 children province-wide are "medically fragile", dependent on technological supports and living at home, which is likely a conservative estimate.[1] Such figures provide an indication of the numbers of children with disabilities who could benefit from health planning support.

With advances in medical technology, a growing number of children with complex medical needs are surviving with their conditions into youth and adulthood (Thompson & Gustafson, 1996; Bradley et al., 1995). Improvements in care and technologies enable children to live at home — often with their parents carrying out technical procedures (e.g. related to tube feeding, respiration, etc.) (Kirk, 1997; DeLong and Boyer, 1991).

This is a diverse group of children — in terms of the age at which they may require technological supports for survival; their ethnicity and culture; whether their medical condition is continuous, intermittent, permanent, temporary, and/or degenerative (Kirk, 1998:102). Such diversity requires that support systems must be responsive to a variety of needs and situations. They must also be flexible enough to adapt as a child's condition, needs, and family situation change.

Many of the issues raised in this report may also affect the lives of adults with disabilities who have complex health needs. There is a significant number of adults with disabilities who face health difficulties. Unpublished research conducted by The Roeher Institute on the basis of the NPHS has found that 37% of adults with activity restrictions (disabilities) rate their general health as only fair or poor, compared with 5% of other adults in Canada. 1.5 million live with a moderate or severe degree of pain

(Statistics Canada, 1994: Table 3). Some 1.9 million use prescription medications on a daily basis. Nearly 900,000 had non-reimbursed expenses for medications in 1991 and nearly a quarter of a million had health and medical services costs that were not reimbursed by any public or private plan (Statistics Canada, 1994: Table 3).

Changing Definitions Of Health

Health is increasingly understood as being about more than illness or absence of illness. Health promotion literature defines health broadly as a "state which individuals and communities alike strive to achieve, maintain, or regain, and not something that comes about merely as a result of treating and curing illnesses and injuries ... it is a basic dynamic force in our lives, influenced by our circumstances, our beliefs, our culture, and our social and physical environment."[2] Health promotion seeks to determine how to enable individuals and groups to make choices that lead to health, as well as to define what strategies and resources are necessary to achieve health and well-being.[3] Strategies to influence the health of children with complex medical needs (and the health of their families) must therefore address a broad range of social and environmental factors which are recognized as having an impact on health.

Shifting Assumptions about Disability

There is growing recognition that disability has social causes and is both a consequence of how society is organized and how the individual interacts with his or her environment (The Roeher Institute, 1994c). Disability is increasingly being framed as a condition of the social environment rather than an individual pathology. This formulation of disability represents a shift away from the conventional bio-medical approach to disability and recognizes that:

- disability is not inherent to the individual
- people with disabilities are an inevitable part of the population rather than an anomaly
- people with disabilities may need support to exercise self-determination in being equals in society (The Roeher Institute, 1996b).

With this changing view of the nature of disability, there is a greater variety of services and support available to people with disabilities which can be accessed outside the walls of institutions.

In 1985 *The Canadian Charter of Rights and Freedoms* guaranteed all Canadians equality regardless of disability. The Charter followed the passing of the *Canadian Human Rights Act* in 1977 which stated that discrimination should not come in the way of human rights regardless of "physical or mental handicap."

Disability is being cast in terms of securing human rights and well-being through social policy. For example, New Brunswick amended their *Schools Act* in June 1986 to endorse the right to integrated education for all children in their neighbourhood schools. Furthermore, employment equity measures and federally supported initiatives that promote inclusion reflect a shifting assumption toward people with disabilities as participating citizens in Canadian society (The Roeher Institute, 1996).

Government Commitment to Deinstitutionalization

There is a growing trend towards getting people with intellectual disabilities out of institutions to participate in the community as much as possible. There are various factors that have led governments in Canada and elsewhere to adopt policies in support of deinstitutionalization (Alberta, 1989; Braddock & Fujiura, 1991; Canada, 1987; Canada, 1993; Canadian Association for Community Living, 1987; Heller &

Braddock, 1985; Knapp, Cambridge, Thomason, Beecham, Allan, & Darton, 1992; New Brunswick, 1985; Ontario, 1987; Ontario, 1993a; Saskatchewan, 1990). These factors include:

- the civil rights movement, human rights legislation, lobbying efforts and landmark court cases (Boschen & Krane, 1992; Canadian Association for Community Living, 1988; Clark v. Clark, 1982; Comité des bénéficiaires du Centre d'acceuil Pavillon Saint-Théophile v. Centre d'acceuil Pavillon Saint-Théophile, 1992; Commission des droits de la personne v. Jean Coutu, 1995; Conroy & Bradley, 1985; Emerson, 1985; Government of Canada, 1982; Human Rights Research and Education Centre, 1990)
- increasing recognition and documentation of the harmful effects of institutional practices (Cook, 1988; Holburn, 1990; Kappel, Burke, Cathrope, Coish, Des Lauriers, & Wray, 1983; The Roeher Institute, 1991; Worth, 1988)
- the desire of families and advocacy groups to shift responsibility for serving people with disabilities from health to social departments in order to reframe disability as a human rights issue, as opposed to a medical issue, and the desire of governments to make this shift for administrative and cost-saving purposes (Canadian Association for Community Living, 1988; Collins, 1992; Peters, 1991; Simmons, 1982; Valentine, 1994; Wegner, 1990)
- state fiscal crises and associated political pressures, especially from the private sector, to contain public health and social service expenditures (Cook, 1988; Knapp, et al., 1992; Zirpoli & Wieck, 1989).[4]

Institutionalization, in many cases, was considered a last resort to obtaining services that were not available in the community (The Roeher Institute, 1995). Some research findings have suggested that people with complex medical needs and with challenging behaviours can be successfully released from institutions provided that there are appropriate supports available to them (Heinlein & Fortune, 1995; The Roeher Institute, 1991). Research and accounts of personal experience also show that enabling individuals to live outside of institutions and inside supportive communities can provide benefits such as increased social interaction and opportunities to exercise choice both in the short term and in the long term (The Roeher Institute, 1991; Whittaker, Gardner & Kershaw, 1991).

Many parents and other family members have long been involved in efforts to replace institutions (Conroy & Bradley, 1985; Richler, 1991). Their struggle has included finding alternatives to large-scale institutions in the provision of health care and services to their family members (Camfield, et al., 1994; Canadian Association for Community Living, 1988; Lightman, 1992). The placement of a family member in an institution has often divided the families and separated the institutionalized family member from life in the community (The Roeher Institute, 1995). Suggesting that a family member move into the community after having lived for so many years in an institution has also been a concern for families. The fear of having to shift back and forth between service provision in institutions and community services was an issue raised among families in the focus groups.

Although the development of community-based alternatives to institutional care can be interpreted as encouraging independent living, it does have its share of problems. The lack of community infrastructure to support the increasing number of individuals leaving institutions is of growing concern to local governments, parents, families, and community advocates.

Deinstitutionalization has also raised a number of concerns for service providers. The nature of the process of

deinstitutionalization has implications for the success of the move both for persons with disabilities and service providers (Fudge, 1988; White, 1992-93). Deinstitutionalization may also affect the role of professionals who have been trained to provide support from within the institutional context and who may now be needed outside the institution in their professional capacity. Deinstitutionalization may result in deprofessionalization of service delivery and decentralization of the management of services. Opposition from some labour groups has influenced policy dealing explicitly with deinstitutionalization (Mendelson, 1994; Racino, 1993; Richler, 1991).

Shifts in philosophy of care

The understanding that a wide range of factors affect a person's well-being is beginning to shape the philosophy of care for children with complex medical needs (Cummins & Baxter, 1997; Broughton and Lutner, 1995). The need to include social factors along with medical status in evaluating well-being is now well recognized. An important part of this shift is enabling children, families, and communities to make choices about the 'what, when, where, and how' of supports to be provided. Research shows that exercising choice and self-determination in the provision of care is essential to improving both health and well-being (Herbert and Milsum, 1990).

Well-being is no longer equated with the absence of disease. People who are terminally ill, for example, can enjoy social well-being when they are a part of a strong social network and have the opportunity to access barrier-free supports and services (Engel, 1989; Herbert and Milsum, 1990). This distinction between health status and well-being helps to shift assumptions about the well-being of children with complex medical needs. Their medical conditions need not define the limits of their well-being, or a vision for their future.

With the shift away from viewing disability as a disease, there are various new alternatives to curative treatments, rehabilitation programming, and other interventions. Changes in treatment modalities are related to *when* interventions take place as well as *where* these interventions take place.

Early intervention techniques are an example of the shift in treatment modalities (Bailey & Bricker, 1984; Bruder & Bologna, 1993; Brynelsen & Cummings, 1987; Marfo & Cook, 1991) as are home-based interventions as opposed to the restriction of treatment to institutional settings (Barrera, 1991; Barrera & Rosenbaum, 1986; Browne, Corbett, Gallant, & Thompson, 1985; Dunst, Trivette, Starnes, Hamby, & Gordon, 1993).

Health Restructuring

All provinces are undergoing major reforms to their systems of delivering health care. These reforms are affecting both hospital and community health sectors (New Brunswick, 1992, 1994; Ontario, 1993a, 1993b; Saskatchewan, 1995). Reforms are being affected by the changing structure of relations between the provincial and federal governments. Some posit that this restructuring is affecting the very principles upon which the Canadian health care system was established (Rachlis & Kushner, 1992).

The Ontario government is focussing efforts on encouraging competition between service organizations to improve the provision, availability, and accessibility of long-term care services in the province. This puts into question the extent to which non-profit agencies will be able to compete successfully against private sector organizations. There could be a striking difference in rates of pay between non-profit and commercial home care providers. This factor should be taken into consideration when analyzing the quality of the service provided as well as the ability of people with complex medical needs to gain access to long-term care serv-

ices. Since some non-profit agencies have higher operating cost structures than the commercial firms, the Ministry intends to develop a "transition plan" to enable non-profit agencies to bid for contracts and become competitive (Coutts, 1996).

Emerging national vision

Along with a shift in the philosophy of care is a broader societal recognition that children, youth, and adults with disabilities are often excluded from enjoying the benefits and advantages of citizenship and inclusion. A recent document, *In Unison*, adopted by all Social Services Ministers — provincial (except for Quebec), territorial, and federal — states that "full citizenship" should be the guiding goal for public policy related to persons with disabilities. Citizenship is defined as inclusion in all aspects of Canadian society, and the commitment by all sectors "to enhance the full and equal participation of people with disabilities."

A citizenship approach to disability is based on the idea that disability is not a deviation or an anomaly, but that persons with disabling conditions are an inherent and inevitable part of society (The Roeher Institute, 1996).

Recent reports by both governmental and non-governmental agencies point to ways that service systems can be designed to foster full inclusion and support for children with complex medical needs and their families. While most of these reports focus on models of service delivery, some have considered a more holistic community response to these issues (*A Strategic Plan for Long- Term Care Needs in Metro Toronto*, Metro Toronto District Health Council, 1997; *A Model for Coordination and Reconfiguration of Services for Children and Youth with High/Complex Care Requirements*, 1995; *Supported Health Planning: A Model to Assist People with Disabilities and Complex Medical Needs and Their Families in Planning for Community Inclusion*, 1999).

2. Emerging Issues

Issues Faced by Children and Families

The amount of time, cost, and energy associated with caring for children with complex medical needs can have many impacts on a family. Often parents must acquire the skills and take on the responsibilities of nurse, service coordinator, case manager, advocate, trainer, and educator among others (Kirk, 1998; Petr et al., 1995; Haverstock, 1992). Caring for a child with complex medical needs can take its toll on parents' physical, emotional and psychological health (Kirk, 1998; Bradley *et al.*, 1995; McKeever, 1991).

The literature points to a number of issues that affect the well-being of children and their parents: the diversity of roles parents must play in accessing services and providing care; social isolation; services that are fragmented, duplicated, and poorly coordinated; lack of personal supports, choices and options; medicalization of need; the limited knowledge base and commitment to citizenship of some service providers and the negative impact on parents' employment opportunities, including limited workforce or academic participation, lost career advancement, and the stress of employers who are not accommodating of the hours that care requires (The Roeher Institute, 1997, 1999; Bradley et al., 1995; McKeever, 1992; Bailey et al., 1991).

Difficulties faced by children and parents arise in part because services and funding are the responsibility of a number of ministries and agencies. However, there is no overarching mandate and commitment to ensure coordinated and responsive supports to children and families (Metro Toronto District Health Council, 1997; Thames Valley District Health Council, 1995; DeLong, 1991). This situation, again, adds extra requirements in the care of their children for parents who have to find and access these services. It is also more likely

that needed information will not reach individuals, families, and even community professionals when services are so fragmented.

Issues Faced by Communities

Creating community support systems guided by a vision of citizenship and inclusion requires significant restructuring. There are a number of issues which limit the capacity for a community to be responsive in meeting the needs of individuals and families: inadequate resources (both financial and human) to meet needs; conflicting and competing mandates of organizations; lack of a framework for sustainable community development and community services which do not proactively promote the citizenship and inclusion of people with disabilities (Hays, et al., 1997).

A major concern reported in the literature is the lack of capacity by government and service systems to address problems in holistic and preventive ways. This is because service systems are often organized to deal with human problems as if they can be neatly divided into distinct social, health, education, and economic needs (Pante, 1996). There exists a lack of infrastructure, planning, and leadership to facilitate community partnerships in the development of services that are comprehensive (McConachie, 1997). Successful demonstration projects show that many different sectors of the community must work together to integrate both generic and specialized supports (American Academy of Pediatrics Committee on Children with Disabilities, 1993a).

3. Developing Community Capacity To Support Children With Complex Medical Needs

The goal of citizenship — through community inclusion and participation — is now recognized as the foundation for developing community capacity to better support children with complex medical needs and their families. A number of recent demonstration projects are showing how this goal can be achieved. Included among these are: Friends, Family, Community: Together project (Alberta); Healthy Families, Healthy Communities (CHNAG, London); the Ontario initiative for implementing the Wraparound process; The Individualized Quality of Life Project (Toronto); The Choices Project (Thunder Bay) and Family-Driven Networks of Support (Massachusetts).

All of these initiatives promote similar features including: commitment and partnerships; accountability; development and management of supports and services; flexible, responsive funding arrangements; individual planning, decision-making network supports and a community development structure and process. Evaluations consistently point to the difference these features make in enabling children to live at home with their families, and in fostering community capacities to provide supports. A number of key factors are essential in delivering an effective community-based approach. Research literature suggests that each of these factors are integral to success and must be considered as elements of a whole system of support and services.

i. Commitments and Partnerships

Government-community-private sector partnerships are essential for the development and delivery of effective, coordinated and comprehensive programs at the community level. Partners can include government from all levels (who have funding or policy responsibilities), business, service agencies, education systems, health care institutions, individuals and family members, and broader community organizations. Partnerships require the commitment of all members — to each other and to a shared goal of citizenship. For government, the

challenge is to ensure flexible, adequate, and sustained funding support, responsive to the shared aims of the partners. For health care and other service providers the challenge is to move beyond their own 'turf', recognizing that no one system can meet all the needs of all children and families (The Roeher Institute, 1998).

The structure of partnerships can vary from quite informal — learning to trust through meetings and dialogue — to more formal arrangements that specify accountabilities and parameters for partnerships (Caledon Institute, 1998). Fostering communication (interactions between family, professionals, agencies, government, and others) has been identified as one of the most critical components in the process of building collaboration for common goals. "Open and honest sharing of ideas, knowledge and skills can lead to a collaborative team process and result in better services for the child" (Beckman et al., 1996).

Partnerships are one of the critical elements for restructuring community support systems to make them more responsive. However, they cannot achieve this goal without putting some other factors into motion. They "are not a panacea for solving all community concerns. Nor should they be viewed as a replacement for government intervention. Partnerships and collaborations would never be expected to replace the role of government in redistributing income and making essential social investments" (Torjman, 1998).

ii. Accountability frameworks

Accountability is another factor in enabling children with complex medical needs and their families to receive the supports and services they need. Research literature suggests three ways that accountability can be assured:

1) A system of planning and coordination support directly accountable to families to assist them in dealing with various service systems and government agencies
2) Accountabilities by governments that ensure that their mandates for funding and resourcing are actually met
3) Arrangements to ensure that partners at a community level make their own policies and practices consistent with the goals and vision of the partnership (The Roeher Institute, 1998).

Taylor et al. (1991), have identified a number of guiding principles to assist service organizations in ensuring accountability to children and their families:

- having a philosophy, belief system, or world view that guides the smallest parts of the staff's work as well as the organization as a whole
- being open to change
- having participatory process and decision making
- having committed and caring leadership
- making people served the focus of their decisions
- being more concerned with doing good than looking good
- not defining themselves in terms of narrow service categories
- being sensitive to the social issues that confront groups faced with discrimination.

iii. Development and Management of Supports and Services

A holistic approach to the development of individualized and comprehensive supports and services must recognize the variety of services that any one child and family may need: health care; social services; income assistance; housing; education; child care; respite; transportation and recreation, to name a few. Across all of these sectors a strategy is needed that will lead to the crea-

tion of services and supports more responsive to the goals of citizenship, community inclusion, and participation (O'Brien and Lovett, 1993; Beckman et al., 1996). Research suggests that such a strategy should include:

- a clear strategic planning process guided by the goals (citizenship, community inclusion, and participation)
- commitment and process for ensuring that staff develop needed skills to work towards these goals
- management that supports, and innovative leadership that champions, the shift to the new goals
- a system for monitoring and evaluating the outcomes of systemic change.

iv. Flexible responsive funding arrangements

Research clearly suggests that flexible, individualized funding encourages delivery of responsive supports tailored to individual and family needs. A review of individualized funding shows that it is effective because: it is flexible; it readily addresses individual needs; it enables access to a larger range of options; it can be readily applied to fostering community involvement; it is responsive to the role families can play; it empowers individuals to have control over their lives and it strengthens awareness on the part of communities to individual/family needs and visions for the future (The Roeher Institute, 1996; Woronko et al., 1994).

A number of methods have been developed to ensure flexible and responsive funding arrangements: reallocation of dollars within programs; transfer of individualized dollars from government to individuals/families; and establishment of community-based funding agencies to allocate dollars to individual plans.

v. Individual planning, decision making, and network support

Research identifies autonomous planning support as critical in ensuring the development of a vision and plan for a child (The Roeher Institute, 1998). Planning support that is independent of service providers and funders ensures that planning facilitators can be more fully accountable to individuals and family members. This support can assist families in planning, decision making and in implementing a plan. Various tools have been developed to guide person-centred planning approaches including: personal futures planning, essential lifestyle planning, MAPS, PATH, and wraparound process. These tools help to create a process of informed decision making through parents sharing their knowledge, expertise, priorities, and vision for their child and family.

Autonomous planning and facilitation does not replace the need for ongoing case management and coordination provided by some agencies. These latter roles are necessary to help the individual and family implement and manage a plan for their supports and life in the community.

Informal support networks can also help to strengthen the planning, decision-making, and coordination capacities of families. Networks help to link individuals and families to both personal and community resources. Support networks assist individuals and families to develop long-term personal relationships that can help to end their social isolation. However, support networks are not developed, nor are they sustained, all on their own. A plan for strengthening community capacity must address how these networks will be nurtured and sustained (The Roeher Institute, 1997).

vi. Community Development Structure and Process

At the heart of building community capacity

lie the following strategies:

- common goals (to meet basic needs, remove barriers to inclusion, build skills, and promote economic development)
- community partnerships and structures to mobilize and exercise shared leadership;
- strategies for investment and reinvestment of community resources
- processes to engage citizens in decision making
- development of new personal skills and organizational capacities
- ongoing monitoring and evaluation (The Roeher Institute, 1998; Torjman, 1998).

Successful community initiatives use such strategies to help make a wide range of specialized and generic support systems more responsive to children with complex medical needs and their families (Metro Toronto District Health Council 1997; Taylor et al., 1991). A community partnership structure (in the form of a steering committee or some other mechanism) is essential in developing public awareness of issues and in creating collaborative strategies.

Community development is a long-term effort that requires ongoing community commitment, support, resources, and management. In order to truly redesign and sustain a responsive support system, all of the factors discussed in this section need to be developed and managed over the long term. This requires a major investment of time, energy and resources. Strategies for maintaining energy and commitment to the community development process may be required to avoid what Mount (1994), has called "the seduction of the quick fix."

Summary

In order for children with complex medical needs to be valued and included in their communities, support systems must be characterized by the six key factors discussed above: commitment and partnerships; accountability; development and management of supports and services; flexible, responsive funding arrangements; individual planning, decision-making network supports and a community development structure and process.

Research suggests that it is not one of these factors on its own that is the solution to creating responsive supports. Effectiveness comes from a community process that incorporates all of these features. The process must enable the partners to jointly adjust and redesign planning, funding, or partnership arrangements as awareness evolves of the needs and vision of children, youth, and families. It is in such an ongoing, community-enhancing process that the goals of citizenship, inclusion, and participation can be achieved.

[1] The number would increase if children in long-term care or acute care facilities were included. At least some of these children could live at home if needed supports were in place. Further, not all children with complex medical needs are necessarily registered at a CCAC. The numbers of children with complex medical needs who require long-term supports are not readily determined because the figures cut across health, social service and education systems.

[2] Epp, Jake. (1986). Minister of National Health and Welfare. *Achieving health for all: A framework for health promotion*. Ottawa: Minister of Supply and Services Canada.

[3] Herbert, Carol, and Milsum, John. (1990). *Measuring health: The documentation and evaluation of measurement procedures currently used to measure well-being*. Vancouver: University of British Columbia, Institute of Health Promotion.

[4] A detailed review of deinstitutionalization processes, evaluation practices, objectives and research issues can be found in The Roeher Institute (1995b).

III.
THE ANALYSIS OF ISSUES IN HEALTH PLANNING

From a practical perspective, what actually has to happen when a child with complex medical needs is born into a family, or returns to live at home? What are the health and service planning processes that children and families undergo for community living? Findings from the literature, interviews and the focus groups point to five stages in the planning process and issues related to each of these stages. Planning process stages are:

- Obtaining planning supports
- Defining needs/Diagnoses
- Making decisions about appropriate supports, services, and treatments
- Arranging for the delivery of needed supports, services, and treatments
- Ongoing planning support and coordination.

1. Obtaining Planning Support

When first gaining access to health care services, children with complex medical needs and their families face dilemmas and issues in obtaining planning support.

Fragmented Access To Planning Support

Families and health care coordinators indicated that individuals gain access to the system of health care services from multiple points:

- Primary care in the community such as general practitioners/family physicians in community clinics and private practice
- Acute care hospitals including discharge planning services, emergency services, and in-patient care
- Mental health services through community mental health associations, community mental health services, and psychiatric/mental health hospitals
- Crisis and emergency response services.

Issues and concerns about health planning and coordination emerge at each of these points. Lack of coordinated planning across these points of entry leads families to experience fragmentation in the supports and services they obtain. Families and physicians agreed that the planning of health-related supports for individuals with disabilities and complex medical needs may begin in a haphazard manner. Such planning involves incorporating information and resources from a variety of sources within institutions and at the community level. The discharge planners and social workers interviewed also agreed that there was fragmentation not only in the way that individuals gained access to information on health planning, but in the way this information was distributed to interested parties.

Inadequacy of Information

Physicians in the focus groups were concerned with the lack of availability of comprehensive patient records especially when the patient was referred by another health care professional, or had spent many years

receiving health care and supports as a resident in an institution. Physicians were apprehensive about the adequacy and accuracy of the information that they received from their patient. They were especially concerned in situations where patients who have difficulty communicating are accompanied to the physician's office by an attendant who knew very little or nothing about the patient and his or her medical concerns.

Consistent with this finding, McGowan & McGowan (1994) have found that medical records are frequently spotty or inconsistent. In other cases, in an effort on the part of health professionals to provide detailed information, health problems become buried in a multitude of data. In residential settings, group homes, or nursing homes, staff turnover may make it difficult to obtain reliable information. Difficulties in securing information about the medical history of an individual who has resided in a facility were also noted in the Family Physician's survey conducted in Ontario in 1991 (Gitta & Deagle, 1992b). Furthermore, in a survey of physicians providing health care to people with intellectual disabilities living in the community in the state of Maine, USA, inadequate medical information was identified as the greatest obstacle to community care.

In one study, physicians expressed awareness of parental displeasure with their failure to provide families with information regarding the disability, or referrals to therapeutic programs based in the community or in public schools. Physicians have also acknowledged parental unhappiness with the content and format of the informing process (Lynch & Staloch, 1988).

Physical Barriers

All focus group participants agreed that many physicians' offices were not physically accessible to people with disabilities. The lack of physical accessibility was characterised by a lack of wheelchair-accessible doorways and ramps to buildings and by waiting rooms that were too small or were poorly arranged to accommodate a patient and her or his attendant. Doctors' offices are also geographically inaccessible to many with inadequate access to transportation (Burns, 1990; Crabtree, 1990; Hayden & DePaepe, 1991).

Communication of Information

Both the literature and information from the focus groups indicated that physicians experience difficulties when communicating with their patients. These may relate to the patient's verbal skills when describing symptoms or providing his or her medical history. The difficulties may also result from some patients and family members having trouble understanding the medical terminology used by doctors (Gitta & Deagle, 1992a). As physicians and families in the focus groups pointed out, this may be because some physicians have difficulty translating complex medical terminology into simpler lay terms for their patients.

Both general practitioners and specialist physicians in the focus groups said that they were not paid to spend more than a short allotted time explaining and communicating information to their patients. Furthermore, these physicians said that the system for remunerating physicians did not recognize the time spent in collecting information to enable their clients to make informed choices.

Parents in the family focus group were unhappy with the way in which they were informed of their child's medical needs. This discontent was significant for them, since initial coping was either positively or negatively affected by the information that was given to them, the compassion shown by the physician, and the listening ability of the physician who gave the news. Physicians in the focus group said it was hard to predict how a parent might react to hearing news about their child's disability or medi-

cal condition. The physicians felt that sometimes patients and their families unrealistically expected that physicians could foresee all possible outcomes for their patients. One of the approaches identified by the physicians in the focus group was to provide the health care information and diagnosis to the individual and his or her family, and then, if possible, refer them to a social worker or nurse who could assist them in getting information on further support.

According to McGowan & McGowan (1994), in a medical model of health care, the rule of thumb is to devote 80% of time-effort to obtaining information on patient history and 20% on physical examination. For people with chronic health problems, the authors place such time estimates at 90% and 10%. Where the environment can play a role in inhibiting, addressing or exacerbating the problem, more time may be needed for observing the environment and collecting enough history to draw proper conclusions about a patient.

Physicians and health care coordinators in the focus groups indicated that a lack of understanding of an individual's cultural experience and mother tongue could also create barriers to providing information about services. Focus group participants suggested that persons with disabilities from ethnic minorities face double discrimination in gaining access to health services. That is, the social stigma attached to having a disability was compounded by discrimination against a person because of his or her ethnicity.

Attitudinal Barriers

It is evident in the literature that accessibility to health planning and health care services is in part dependent on the attitude of health care professionals toward patients with disabilities. Studies indicate that health care providers may experience fear or discomfort in the presence of people with an intellectual disability. They may have negative attitudes that lead to the rejection of patients or the denial of life-sustaining therapies (Minihan, Dean, & Lyons, 1993; Hingsburger, 1987). This finding was supported by the physicians in the focus groups who recalled how some of their medical colleagues were concerned that the needs and behaviours of people with intellectual disabilities might upset other patients in physicians' waiting rooms.

Family members in focus groups described a number of incidences they felt were based on discrimination relating to intellectual disability. In one case, parents in the focus group described their perception that because of their child's intellectual disability, an ophthalmologist was negligent in conducting routine eye check-ups and prescribing needed glasses. Parents reflected on their experiences in emergency units of hospitals, where people with disabilities were often the last to be treated. It was suggested by families and physicians in the focus groups that emergency room staff were often uncertain about how to deal with a patient with an intellectual disability, and that their needs were seen by some to be less immediate than others.

2. Defining Needs And Making Diagnoses

There is a distinction between medical assessments of individuals with disabilities and assessments of the support needs of individuals and their families. In addition to medical services, supports are needed in the environments in which individuals and their families live, learn, and enjoy leisure. Assessing such needs can be referred to as an "environmental diagnosis."

The process of defining needs and making a diagnosis requires attention in the design of health planning. Focus group discussions revealed how needs assessments and diagnoses determine the kind of services and supports an individual is able to access.

Medical emphasis in needs assessment

According to family members in focus groups, physicians tend to emphasize the medical aspects of their patients' needs. With the emphasis on the diagnosis of illness, families felt that a broader understanding of the individual's needs — needs which may require supports other than health care services — were excluded.

Dual Diagnosis

The fact that a person has both an intellectual disability and a psychiatric disability may affect the kind of service that they receive. The family focus group conveyed that these individuals face particular difficulties in gaining access to non-psychiatric related health care services because of "dual diagnosis."

Family members spoke of being referred back and forth between health care specialists and community mental health services, because the respective professionals made opposing diagnoses regarding whether a problem was related to intellectual disability or mental health. Individuals would be sent back and forth between offices, always told they belonged elsewhere. On the other hand, some psychiatrists have looked solely at the psychiatric label and referred people with mental health problems and an intellectual disability to psychiatric facilities. These individuals usually received high dosages of medication to the exclusion of other supports or interventions.

Family participants in the focus group recalled experiences where their family member had been restricted from gaining access to primary and acute care services because a diagnosis was required to receive services. For example, one focus group member recalled that when her daughter who had an intellectual disability and a mental health disability was in a mental health crisis, the community mobile crisis unit said that there was nothing they could do. The local hospital had deliberated for six hours because they could not find a diagnosis that could be used to admit her. Similarly, several families had the experience of being turned away by primary care hospitals because their child had both an intellectual and psychiatric disability. The parents were told to turn to psychiatric institutional health care instead.

Several of the participants in the focus group of families stated that "mental health problems" or "challenging behaviours" were used by various authorities as the justification for withdrawing individuals from their school placements and vocational and residential supports.

These concerns are mirrored in the 1995 Metro Agencies Representatives Council report on dual diagnosis. The report concludes that although individuals with intellectual disabilities experience the same range of mental health problems as the general population, they experience a much higher rate of these problems than the general population (MARC, 1995). Furthermore, the mental health needs of individuals with disabilities are significantly underserved, with waiting lists of six months or more for mental health services in certain areas of the Greater Toronto Area (MARC, 1995).

Focussing on disability as a medical need

Physicians unfamiliar with disability-related conditions may focus inappropriately on people's disabilities rather than on their health problems (Burns, et al, 1990). Families in the focus groups expressed a concern that physicians did not commonly take into consideration the family context of their patients (i.e., whether or not the parents have a steady income; where the patient lives; if she or he is isolated in the community; the kind of supports that exist in the patient's community; the number of hours

of care the family member is currently giving to the person with a disability; and whether or not the family member who is the primary caregiver is receiving medical attention or has access to a support network). Rather, the medical diagnosis was the primary focus in interactions between physician and patient. The environments with which the individual interacted were rarely, if ever, considered.

3. Making Decisions About Appropriate Supports, Services, And Treatments

Making decisions about appropriate supports, services, and treatments involves reflecting upon the needs of the individual and how to best respond to these needs. Focus group participants have encountered two key issues when they have had to make decisions about supports, services, and treatments.

Diversity of knowledge

The focus groups revealed that there are several kinds of knowledge being used and referred to in health planning. These include: clinical knowledge among medical professionals; knowledge of an individual's "person" by the physician; the patient's self knowledge and knowledge of the process of health planning and service provision. The literature refers to another form of knowledge called the "knowledge of function and process" which relates to understanding the nature of illness and disease and functional changes in the person (Cassell, 1995). This reflects the clinical knowledge referred to by the focus groups.

Participation in decision making

Parents and health care coordinators felt that often physicians did not respond positively to their input into decision making and their request to explore alternatives to primary health care. The physician's knowledge tends to predominate over the perspectives and wishes of the families in the decision-making process.

Families experience variation between paediatric and mental health professionals in terms of participation in decision-making processes. Some parents have felt more involved in the process of decision making when paediatricians were present than when mental health professionals were involved with their children. Others have felt that the process of decision making is never consistent among the health care professionals with whom they are in regular contact.

The physicians in the focus groups spoke of situations where parents who were in a position to make decisions were reluctant to rely entirely upon a physician for making decisions about care and interventions for their child. In such situations, it was clear to the physicians that the parents wanted to be the decision makers and to be recognized for their knowledge of their child and his or her interests. The literature shows that parents want to participate in decision making. Lynch and Staloch (1988) found that parents valued physicians, and school and public health nurses who showed respect for parents' knowledge and judgement, and who were available on a regular basis. Families, however, suggested that their views were at times ignored or undervalued by the health care professional and that this could undermine an open and mutually respectful relationship. This point is also reflected in the literature, but Nursey, Rohde, & Farmer (1990) add that health care professionals also indicated that their views are often ignored by their patients.

Families in the focus group felt left out when it came to knowing exactly what the physicians were doing when treating patients. Families possessed knowledge about the day-to-day activities of their family member of which physicians were not necessarily aware. Furthermore, parents felt

that their knowledge had not been consistently factored into any assessments made by professional medical staff. Physicians in the focus group said that in their practice, some families did not want to know all the details about the treatment of their family member; they just wanted to know what the physician's expectations were for the patient. Physicians expressed that some families put very high expectations on the capabilities, powers, and know-how of physicians.

4. Arranging For The Delivery of Needed Supports, Services, And Treatments

Individuals encounter several issues in the planning for *how* and from *where* supports, services, and treatments are to be delivered.

Regional variation in delivery limits access to needed services

Both physicians and family members in the focus groups identified that regional variation in delivery limits access to needed services. They point, for example, to inconsistencies in emergency services between areas within the same city or region, in terms of their ability to adequately respond to the needs of people with disabilities. Furthermore, physicians had difficulties in providing patients with referrals to health services that fell outside the immediate region which they served. Physicians agreed with families that they do not always have information on the availability of specialized services outside their region. Even if they do know of the type of support that their patient may need from the community (i.e., nutritionist, home care) they may have to rely on others such as a nurse or health care coordinator to determine the availability of such services. The patient may have to travel long distances in order to get the required care.

Access to community-based supports

Families have found that physicians often lack information about specialized services and supports available for people with disabilities. Of the 75 family doctors who responded to the University of Western Ontario survey question on information and supports, 73.2% felt that they needed more information in this area (Gitta & Deagle, 1992a). Family physicians called for more information on social services, rehabilitative services, specialized medical services, and specialized psychiatric services.

The family focus groups indicated that finding appropriate community-based services has been a difficult task for them. Parents indicated frustration with medical and social service personnel who were trained to find institutional rather than community support options for persons with intellectual disabilities. This, they felt, was a major obstacle in obtaining information on community-based supports. Health care coordinators indicated that the skills of many service providers who work with people with intellectual and mental health disabilities are often not recognized.

Focus groups revealed a gap between what health professionals felt they could realistically know about specialized services and what families felt were needed if adequate support is to be provided. Paediatricians, for example, said they frequently serve patients who live outside the region in which their practices are located. They felt that it was unrealistic to expect them to know about the services that were available in their patient's community. On the other hand, families described how mental health specialists, such as psychiatrists, often lack knowledge about supports in the community for people with disabilities. This means, in effect, that these physicians are often unable to provide the support needed by families.

Gap between paediatric services and adult health care

The current gap between paediatric and adult health care has significant negative implications for children and youth with disabilities and complex medical needs. All the focus groups recalled problems arising when adolescents with disabilities made the transition from the paediatric system to the adult health care system. During this transition, the paediatrician's knowledge of the adolescent's changing needs was not easily transferred to practitioners who provided health care to adults. Coordination of care is inhibited both by this breakdown of communication and a persistent lack of needed services for youth. The family physicians and specialists involved in the focus groups indicated that as a result of this gap many persons aged 18 years and older have been utilizing services that target children. Families in the focus groups described situations where health care providers treated their adult family member with an intellectual disability like a child. Physicians agreed that an "infantilization" of adults with intellectual disabilities was prevalent.

Transferral of knowledge and technology

Physicians, families, and health care coordinators in the focus groups indicated that families were often concerned about having to make frequent visits to the hospital in order to gain access to needed technologies (e.g., dialysis machine). Furthermore, family members in the focus group recalled times when they did not feel adequately informed to administer the technology themselves in the home setting — this alternative had not been presented to them. Physicians, health care coordinators, and families were all concerned about the lack of knowledge about transitional services and related concerns when a person moves from institutional to community care. They questioned how a smooth transition of care from the institution to the community was to occur when not enough was known about the availability of health care and social service supports at the community level.

5. Ongoing Planning Support And Coordination

Planning support and coordination on an ongoing basis is necessary to ensure that the changing needs of individuals with disabilities and their families are met. Focus group participants provided a variety of reasons for ensuring the availability and accessibility of ongoing planning support and coordination.

Ensuring ongoing basic health care services

Families shared concerns that in their experience, physicians did not encourage standard health care procedures for health promotion (i.e., routine breast examinations and basic health check-ups). All focus group participants called for more preventive measures and a means for ensuring that support providers take people with intellectual disabilities for routine check-ups rather than waiting for a medical crisis to occur.

With assistance in planning and coordination, such routine check-ups can be scheduled and preventive health care measures taken. Fostering attention and awareness among health care providers to the ongoing health needs of people with disabilities who have complex medical needs may assist in counteracting problems such as the over-use and over-prescription of medication.

Professional involvement in determining health outcomes

Physicians in the focus groups were aware that information about patients and diagnoses tends to be passed from one health

care professional to the next. Such information, in their view, is not always treated with the respect and confidentiality it is due. A number of ethical questions emerge out of these concerns. What type of patient information could be shared and what should remain confidential? What controls should be put into place by physicians and patients regarding the burgeoning international network of electronic information that has increased the capacity for the open exchange of information?

Lack of coordination between health and social services

The fragmentation and the lack of coordination within and between health and social services for people with disabilities is a concern that has been voiced by consumers (Foreman & Neilands, 1991; Lord, 1988; Sloper & Turner, 1992; Wilgosh & Chomicki, 1991), governments (Ontario, 1991), and health care professionals alike (Meyers et al., 1998; University of Western Ontario, 1995). Families experienced this fragmentation as they were referred from one department to the other when trying to collect information on health care and disability-related supports. Physicians also were frustrated when trying to obtain basic information on disability support and aids and devices and were often unsure which government department had jurisdiction. In such cases, discharge planners and health care coordinators were consulted in order to obtain the information.

The work of planning and coordination — arranging visits to health care providers, managing information flow and communication, following up on decisions taken, preparing plans, and obtaining funding for social supports — were all essential and time-consuming tasks, according to the focus groups. In most instances, families in the focus group had become their own health care and social support coordinators, often with little help or direction. In such situations, one parent usually devotes many hours per day or per week to the process. Family member respondents pointed to the importance of a person to assist them in this process of coordination, while enabling the individual and the family to remain in the driver's seat in terms of planning and decision making.

The focus group participants indicated that despite the need for them, coordination supports were often unavailable, unresponsive to the particular needs of persons with disabilities and their families, delivered in ways that put coordinators in conflicts of interest, or designed with very restrictive eligibility requirements.

Limitations to the role of physician

Physicians are not in a position to provide ongoing planning support for a variety of reasons, many of which are due to funding and time constraints. Under the fee-for-service model, a physician is paid according to the number of contacts made with patients, rather than on the length of time spent with each patient. A number of focus group participants were concerned that physicians do not spend enough time with patients who have intellectual disabilities because of the funding incentives to see more patients. Consequently, people with disabilities and their families have had to come back for many appointments when one longer appointment would have been sufficient in the first place.

This is not to say that all doctors feel limited by the fee structure. Many of the physicians in the focus group felt that the fee-for-service system was effective, but needed some modification so as to better deal with the time management factor and the complexity of cases that physicians face on a daily basis. This concurs with family physicians surveyed in The University of Western Ontario study. Over 90% of respondents indicated that it took them longer to see clients with intellectual disabilities. Forty

percent of this group said that it took them 50% more time to see clients with intellectual disabilities, while 37.3% indicated that it took them 25% longer (Gitta & Deagle, 1992a). The literature reveals that physicians have difficulty juggling the greater amount of paperwork and documentation and the longer periods of time spent with clients with intellectual disabilities (The University of Western Ontario, 1995).

Most of the physicians involved in the focus group had at one time or another advocated for patients with disabilities when they needed support in other areas of community relations (e.g., putting a child with a disability into an integrated classroom setting). However, these physicians pointed out that the health care system has not recognized or supported the role of the physician as a community advocate or family advocate on a temporary or an ongoing basis.

Ongoing decision-making process

All the focus group participants were concerned that legislation that deals with consent provisions would have negative impacts for adults with intellectual disabilities. It was argued that this legislation may trigger capacity and competency reviews ultimately leading to the suggestion of guardianship. All the participants felt confused about the changes in legislation on consent and decision making in treatment. While concerns focus on the legal and ethical repercussions of consent and guardianship legislation, doctors are concerned about implications on how they practise medicine. Families are afraid that individuals with intellectual disabilities may be denied health care because of the complications for doctors in making sense of the new legislation.

Physicians and families in the focus group expressed a need for doctors to have information that clearly defines their rights and responsibilities with respect to consent and substitute decision making. They suggested instituting formal consent procedures in order to avoid situations where a physician may refuse to treat an individual for fear of legal repercussions related to the issue of consent. Furthermore, families were concerned that a physician might give treatment without consulting the patient or the patient's guardian. Physicians felt conflicted between the need to give care efficiently and effectively in emergency and life threatening situations, and the need to go through formal procedures that may take too long and therefore put a person's life in further danger during an emergency situation.

For many doctors, the ethical problems encountered in daily practice have been complicated or intensified in providing health care for individuals with intellectual disabilities (Gitta & Deagle, 1992a). Some examples of ethical problems that physicians discussed in the focus group, also evident in the literature, included: parents who request that their children with a disability (usually female) have surgical sterilization or hysterectomy "for their own good" (Gitta & Deagle, 1992b) and parents who consider tubal ligation in cases where the individual with a disability has been subject to continuous sexual abuse, rather than attempting to take steps to eliminate the cause(s) of the abuse.

6. The Need For Planning Support

People with disabilities and their families face many difficulties in gaining access to needed health and social supports. Consequently, too many individuals are institutionalized in acute and long-term care facilities. Others remain in the community, but without the adequate supports to meet their basic needs and those of family caregivers, let alone to participate fully and actively in community life.

One of the main difficulties faced by people with disabilities and their families is in obtaining planning support to assist them in developing a network of community

resources and supports that will sustain their inclusion in the community. Access to planning supports through the health and social service systems is fragmented. Planning is usually not accountable to individual and family goals and decisions. Information is lacking about where to go for supports. Physical, communication, and attitudinal barriers in the health care system restrict access to needed health care resources.

When people do get access to health care services, there tends to be too much reliance on medical interventions as the solution to problems. Less attention is given to how health care resources can support people to overcome the barriers to fuller participation in all that their communities have to offer — family life, personal relationships, social and cultural organizations, recreation, education, and employment.

Making decisions about how to support a person with a disability, who may also have complex medical needs, involves many factors: an individual's and family's vision for life in the community; how to provide health care and social supports so a person can live at home with their family or elsewhere in the community; the barriers to full participation in education and other systems, and how these can be overcome; how to manage response to emergencies and how to support families and communities so they can provide ongoing care and support.

Arranging needed supports and services for a family member with a disability is usually an all-consuming task — searching for needed funding and supports; if one is lucky, working with three, four, and more agencies, but within their constraints and mandates; managing staffing schedules; dealing with the constant challenge of limited funding; obtaining respite care so families do not "burn out" and finding time for other family members. For those trying to balance paid employment with the responsibilities for caring for a family member with a disability and medical needs, the challenges are even greater.

Summary

A variety of issues in health planning have been identified through the focus groups with health care coordinators, family physicians, paediatricians, and families who have members with disabilities and complex medical needs. Health planning has not been conducted in a manner that is conducive to an understanding of the individual as a whole person with a diverse set of needs. Individuals with complex medical needs have not been provided with a diverse set of options. In many cases, where their needs have been assessed in a medical framework, individuals have been restricted in their choice of, and access to, supports. Essentially, a new way of providing health planning to this group is required. The next step in the process of developing a model for health planning for this population is to identify current models of health planning and the characteristics of the environment in which health planning is taking place.

IV. MODELS OF HEALTH PLANNING

1. Existing Models of Health Planning

A survey of existing models in health planning was conducted in light of the context in which health planning takes place, and the health planning issues identified by the focus groups and in the literature review. The current context supports four models of health planning. These models are differentiated by the way in which they define needs; their scope of services and supports; the providers of planning support; the indicators used in assessing health outcomes and who controls the determination of health outcomes. The models are:

- *The health care professional model* which bases delivery of health care and social services on a medical diagnosis. Clinically indicated health outcomes are determined by health care professionals.
- *The multi-focussed team model* which combines the efforts of a team of health and social service professionals led by a health care professional. The team assesses needs, provides health care and social supports, planning support, and determines health outcomes. Health outcomes are indicated by both clinical and social factors.
- *The self-managed care model* which places the responsibility for and control of the determination of needs, health outcomes, and the provision of planning support with the individual. The scope of services and supports which addresses the individual's needs includes health care and social supports as well as alternative arrangements. The range of indicators of health outcomes is broad and varied.
- *The family-centred model* which recognizes the family as the leader of the decision-making process around planning support. The family collaborates with service providers to identify needs and to determine health outcomes. The family environment and the home context are primary considerations in identifying service and support options and determining indicators of health outcomes.

A comparison of these models is provided in Table A. Appendix C provides examples of established programs of health planning from which these model categories were developed.

The next step in the analysis identified links between the elements in the existing models of health planning and the key concerns and suggestions made by participants in the focus groups. Three elements were discussed by the focus groups that were not addressed in the existing models: (1) the steps in obtaining planning support; (2) the roles of individuals in the decision-making process and (3) the need for ongoing planning support.

Current health planning approaches and their measured outcomes tend to be medical. Health outcomes such as greater personal autonomy, strengthened support networks, and improved quality of life are not necessarily factored into current health planning practices. The need for ongoing planning support is also tied to the person's primary environment. If the person spends

TABLE A

Models of Health Care Planning

Elements	Models				
	Health Care Professional Model	Multi-focussed Team Model	Self-managed Care Model	Family-centred Model	Supported Health Planning Model
Definition of Needs	based on medical diagnosis	based on assessment by team led by health care professional	primarily determined by individual	based on assessment by the family in collaboration with service providers	personal and environmental needs as identified by the individual, family, and personal network
Scope of Services and Supports	focus on health care sector	focus on health care and social supports	focus on health care and social supports as well as alternative arrangements	focus on the need for choices and options for families within their home environment	range of choices and community-based options
Providers of Planning Support	health care professionals pre-eminent	responsibility of multi-focussed team	responsibility of individual	family is recognized as the leader in the decision-making process	individual and family have access to accountable support
Indicators of Health Outcomes	limited to clinical indicators	range includes clinical and social indicators	range of indicators is broad and varied	range of indicators is determined within the context of the family	range of indicators is diverse
Who Controls the Determination of Health Outcomes	health care professionals	multi-focussed team	individual	family in collaboration with service provider	range of indicators determined by individual and family

most of his or her time in the hospital/institutional context, then needs are more likely to gain formal consideration. For those living at home there is no formal, ongoing monitoring mechanism that identifies the individual's changing needs with respect to the home and community. [1]

Health is increasingly understood as more than illness or absence of illness. In Canadian public policy, health has been defined more broadly as a "state which individuals and communities alike strive to achieve, maintain, or regain, and not something that comes about merely as a result of treating and curing illnesses and injuries ... it is a basic dynamic force in our lives, influenced by our circumstances, our beliefs, our culture, and our social and physical environment."[2] Health promotion focuses on providing individuals, groups, and communities with the tools to exercise greater control over the resources and strategies necessary to achieve their health and well-being.

These models of health care planning have several benefits in providing support for some, but not all, the needs of an individual and his or her family. They draw on expertise among community and medical professionals in collaborative and team approaches to planning and coordination. However, the models fail to address key issues, in particular that *health planning is more than health care planning;* that supports are needed for individuals and families to direct their own care and supports and that investment is needed in order to develop community-based support.

2. Benefits and Limitations of Existing Models

In order to develop a new model of health planning that can begin to address the needs and concerns presented by the focus groups and in the literature, it is necessary to identify the benefits and the limitations of existing models of health planning.

Support provision for a wide range of health needs

Health planning needs for individuals are usually identified through assessment processes (Lakin, Larson, & Prouty, 1994). The existing models provide planning support and treatment for needs that are medically diagnosed. The majority of existing models of health planning do not consider the needs of the individual in relation to contexts that are external to the acute care setting.

None of the models acknowledged that the individual with complex medical needs may have connections to a variety of environments. The emphasis on a "medical" assessment is also because the "medical" aspects of the individual's needs are the focus of the acute care hospital setting.

Expertise in planning support among community and medical professionals

The models recognize that various individuals have expertise in planning support. These individuals include medical professionals such as physicians and nurse practitioners, as well as a variety of community representatives, families and individuals with complex medical needs. All but one planning model considers that these planning "experts" work collaboratively in developing health plans. However, the physicians and health care coordinators in the focus groups indicated that most decision making around health planning involved the input of more than one health care professional, even if the health planning process was not formally recognized as a collaborative one. In such cases, the physician was the leader of the health planning process.

Collaborative team approaches to planning and coordination

The multi-focussed team model formally recognizes the importance of involving more than one person in the process of health planning. In this model, a variety of health care professionals, community support providers and family members may be involved in the definition of needs and in planning support. The medical approach to health planning also involves collaboration, however, this process includes health care professionals only.

Health planning is more than health care planning

Existing models of health care planning rely on medical solutions to the complex health problems of individuals, viewing health primarily, if not solely, in medical terms. Significant attention has not been given to the possibility that the long-term support needs of the individual could be better addressed through non-medical supports. Other factors such as income, living arrangements, and the support of family and friends tend not to be given the same consideration as medical records when needs are identified. Essentially, such models apply the conventional medical model to planning for health (Criscione, Kastner, O'Brien & Matheson, 1994; Griswold, Msall & Cooke, 1987; Morrisey, Calloway, Bartko, Ridgely, Goldman & Paulson, 1994).

Supports for individuals and families to direct their own care

Focus group participants pointed to the importance of providing families with support to enable them to make decisions about health care and health planning. Although the existing models of health planning recognize that individuals and families can direct health care and health-related services, none consider the provision of decision-making support. The family-centred model acknowledges that families play an integral role in decision making, but does not provide them with support to maintain an open dialogue with service providers and health care professionals. Likewise, the self-managed care model does not recognize the need for this kind of support. This model assumes that the individual is able to independently manage and coordinate health planning and service delivery around her or his own needs.

Investment in developing community infrastructure

None of the existing models of health planning address the need for developing the community infrastructure to provide individuals and families with support in health planning. The focus, once again, is on providing such support in the acute care setting. Community infrastructure may be required in the provision of respite for family members who are providing support. Further investment in the development and enhancement of support around the individual and family could ensure that adequate respite is available.

Conventionally, most of the understanding of social inclusion has focussed on the individual's social skills (Craig & McCarver, 1984; Hill, Lakin, Bruininks, Amado, Anderson & Kopher, 1989) with special emphasis on his or her adaptive behaviour (Hill et al., 1989) and avoidance of risk (Taylor, Asher, & Williams, 1987). On a systemic level, however, social inclusion is heavily influenced by the extent to which the service systems, including health care and education, have promoted and provided opportunities for social interaction and community involvement (Abery & Fahnestock, 1994; The Roeher Institute, 1996a).

Summary

A proposal for a new model of health planning was developed based on analysis of existing models, focus group findings, and the review of the literature. Exploring the links and the gaps between these information sources pointed to critical areas in health planning to be addressed by a new model. The purpose of this model is to enable health planning for people with disabilities, and is intended to ensure that the needs of those individuals with complex medical needs are not overlooked.

[1] Family physicians have often played the role of providing on-going monitoring, however, it is important to note that not everyone has had a family physician or, has maintained the same family physician from childhood through adolescence and into adulthood.

[2] Jake Epp. Minister of National Health and Welfare. (1986). *Achieving health for all: A framework for health promotion.* Ottawa: Minister of Supply and Services Canada.

V.
THE SUPPORTED HEALTH PLANNING MODEL[1]

The supported health planning model builds upon the strengths of existing models of health care planning. It draws on the availability of professional expertise, health care professionals, and experience in collaborative and team approaches to planning, as these are required, and recognizes the importance of individual self-determination as in the self-managed care model.

Supported health planning is based on a recognition that the barriers people with disabilities face in society have little to do with particular physical or intellectual differences. Exclusion results much more from health, social service, education, and other systems which have tended to limit people's access to supports that enable their full inclusion in communities.

Supported health planning addresses the limitations existing models pose for people with disabilities and their families in the following ways:

- Personal and environmental needs are identified primarily by the individual and family
- Individual and family have access to independent, accountable support in planning and coordination of supports — they do not have to manage all on their own
- Individual and family have a range of choices and available options for health care and social supports
- Community supports are enhanced by the system of policies, programs, and funding to meet the needs of individuals and families
- Health outcomes are defined by the individual and family.

Aim and principles of the Supported Health Planning Model

The aim of the model is to promote the well-being of people with disabilities, who may have complex medical needs, and their families. It is based on the goal of health promotion to enhance an individual's and family's control of the factors affecting their health and well-being. This vision of health planning is grounded on the assumption that health is an important resource in enabling the self-determination of individuals and their families in their day-to-day lives. The following principles guide the supported health planning model:

- *Self-determination*: Individuals and their families will be supported in planning for and meeting needs that assist them in achieving their personal aims. The process will enable people to identify opportunities, develop resources, and build individual and community capacities that promote their health and well-being.
- *Equal respect for persons*: Health planning that will promote mutual respect and recognition between people regardless of disability, genetic make-up, religious belief, gender, race, or ethnicity. Health planning supports will address disadvantage and recognize that people have differing needs.

- *Community-based*: Health planning supports that will assist children and families to live full lives in the community and to enjoy opportunities for family life, personal relationships, recreation, education, training, employment, and other types of involvement. Health planning supports will be available regardless of where people live and will expand the range of choices for health and social supports in the community. It will look beyond the traditional service systems to transforming existing and generic community supports in ways that better meet the particular aims and needs of individuals and their families.
- *Accessibility*: Health planning support that will be accountable to individuals and families and available to those who require it. Planning support will be provided without regard to nature or extent of disability or complexity of health and medical needs.
- *Shared accountability*: Governments, physicians, and health care and social service providers will share accountability for ensuring that health planning according to these principles is recognized, respected, and supported. They will work in collaboration, interdependence and dialogue to ensure responsiveness to goals, plans, and needs that individuals and families define.
- *Effective public administration*: Public support for delivery of accessible and accountable health planning will be recognized as integral to ensuring equal access to the health care system. However, health planning may be facilitated in a variety of ways, and governments need not deliver health planning supports directly.

Action plan for supported health planning

Health planning is an ongoing process that takes into account the changing needs of individuals and families and the diverse *relationships and environments shaping* their lives. An individual's medical needs will be integrated with other factors that have an impact on his or her health and well-being, including social support and other resources.

Supported health planning begins with individuals and families defining their own needs as they bring focus to the environments they are a part of (home, community, school, etc.) and the environments they wish to be a part of. Supported health planning emphasizes ongoing planning assistance that enables a person to live in the community, in a place that he or she can call "home". Health planning can begin at any point in a person's life, and from any point in the health care system. It is a process of dialogue, discovery, and development of needed resources. There are five stages in the process, some or all of which may happen simultaneously.

Stage 1: Obtaining Planning Support Through A Planning Facilitator

Individuals and families may want to plan on their own, or they may wish assistance in planning and coordination. In the supported health planning model, individuals and families can obtain this assistance from a planning facilitator accountable to them. Accountability of the facilitator is ensured through their independence from health and social service providers whose services may be needed, and from government or other funding bodies who may directly fund individuals and families.

Supported health planning is not case management in the traditional sense. Families, rather than professionals, direct the plan and thus are not treated as social and medical cases. The individual and family must be involved in the process to select a planning facilitator to maximize their con-

trol in planning. The planning facilitator is not a medical or health services professional.

The role of the planning facilitator is ongoing. He or she maintains an integral role in evaluating and monitoring the health and social supports put into place, and is available to assist individuals and families in changing health plans as their goals and needs change.

Stage 2: Identifying Actors

Supported health planning aims to initiate a process of dialogue in which a vision for life in the community takes shape, of discovery of possibilities for realizing that vision, and of development of needed resources. A range of actors can be helpful in assisting individuals and families to identify possibilities and options — health care providers, social service agencies, teachers, neighbours, and friends. Actors who can play a role, and whom individuals and families wish to be involved, are invited to participate. The actors should be linked in some way to the kinds of environments that the individual and family are a part of, or wish to be a part of.

Stage 3: Individual and Environmental Diagnosis

At this stage in the planning process, individuals, families, and other actors involved think about a vision for the individual's and family's life in the community. In doing so, they consider the places and environments the individual will be a part of, or wants to be a part of (whether at home, school, or in another community setting). They look at how these environments help or hinder full inclusion of the individual. This analysis helps to identify the particular needs for support, and the changes in the environments that must be sought.

Identifying the needs of the individual as they relate to his/her vision for life in the community, and the environments he or she will be a part of, is vital. Needs should not be identified only in relation to a functional or bio-medical assessment, or simply in relation to the availability of resources. Participants in the planning process who are linked to the environments of the individual can identify resources and explore how to make the environmental or structural adjustments necessary to ensure that the goals and needs of the individual and his or her family are met.

Stage 4: Designing and Activating the Network of Resources

A person's network of resources may consist of several components including human resources, fiscal resources, knowledge, organizational resources, and technical resources (e.g. ramps, medical equipment, physical accommodations, accessible transit). Designing the network includes: identifying and obtaining the personal, financial, and other resources that are necessary to achieve individuals' and families' goals; developing action plans to identify and overcome environmental barriers and establishing plans to coordinate and manage the network.

Stage 5: Monitoring and Evaluation

In order to ensure that the network of resources is accountable to individuals and families, and is flexible and responsive in an ongoing way, it is necessary to identify outcomes important to the individual and family; establish ongoing monitoring and evaluation to ensure that needed supports are in place and environmental adaptations are being made and identify resource options and choose the most cost-effective ways of reaching the goals.

A number of expected outcomes have been identified that may be used as a part of the monitoring and evaluation process.

Outcome 1:

Individuals and families have timely access to health and social supports that are coordinated in a way that is responsive to their particular needs as they defined them. Based on the principle of self-determination, needs will be defined in relation to the goals of individuals and families.

Outcome 2:

Needs assessment has been based on a comprehensive view of the person and his/her environment and has not been limited to functional evaluation or medical diagnosis. This outcome is based on the principle of equal respect for persons. An individual and his or her family will have been respected throughout the process of health planning. The process will focus on the whole person and his or family — their aims as well as their needs.

Outcome 3:

There has been a mechanism in place for the effective sharing of information to ensure that the individual is the guardian of that information. Ensuring that families and individuals have control of information promotes their participation in the process of supported health planning.

Outcome 4:

Individuals and families have had control in decision making. (This assumes that individuals and families have adequate support to do so). Meeting this outcome requires that the individual and his or her family have played a central and important role in decision making and in the exploration of a wide range of options.

Outcome 5:

A health promotion approach has been used and health status improves. The supported health planning model is based on an assumption that a health promotion approach will create the conditions for improvements in health status. Health promotion focuses on increasing the control of the individual over resources and conditions affecting his or her life, strengthening networks of supportive personal relationships, and creating healthy community environments.

Outcome 6:

Community capacity to include and support individuals with complex medical needs has been strengthened and supported. Planning supports assisted the individual and family in obtaining needed community-based resources. Individual and family needs were recognized in the community, and real changes took place to secure their community inclusion.

A more detailed review of the Supported Health Planning Model can be found in The Roeher Institute. (1999). *Supported Health Planning: A Model To Assist People With Disabilities And Complex Medical Needs, And Their Families, In Planning For Community Inclusion.*

CONCLUSION

People with disabilities and their families are seeking their rightful place in communities. They face many barriers to securing the self-determination, equality, and citizenship that most Canadians take for granted. Supported health planning is one tool to assist people in confronting these barriers. It is based on a recognition that health care, other publicly-funded and regulated services, and communities are for the equal benefit and advantage of all citizens.

Supported health planning assists individuals and families in defining a vision for life in the community, and then for identifying how health care and other supports will help to make that vision a reality. Medical services are paramount for people with disabilities who have complex medical needs, but they need not define the limits of the possible. Too often this has been the case.

By beginning to redraw the network of resources to support individuals and families in a way that includes health care, social services, schools, and community organizations, supported health planning redefines the "art of the possible." For individuals and families this means a fuller life in the community. For communities, this means new capacities to accommodate and support diversity. For health care institutions and governments this means that the goal of securing more cost-effective community options can be achieved. For Canadian society, redefining the "art of the possible" to fully include people with disabilities and their families means that we are that much closer to realizing our collective commitments to citizenship and human rights.

REFERENCES

Abery, Brian H. and Maurice Fahnestock. (1989). "Enhancing the social inclusion of persons with developmental disabilities." In Hayden, M.F. and B.H. Abery (Eds). *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities.* Baltimore: Paul H. Brookes.

Alberta. Alberta Legislative Assembly. (1989). *Claiming my future: A person with a mental disability - today and tomorrow.* Report of the Brassard Review Committee. Edmonton, Alberta: Alberta Legislative Assembly.

American Academy of Pediatrics Committee on Children with Disabilities. (1993a). "Pediatric Services for Infants and Children with Special Health Care Needs." *Pediatrics,* 92, pp. 163-165.

Appleton, P.L., V. Böll, J.M. Everett, A.M. Kelly, K.H. Meredith and T.G. Payne. (1997). "Beyond child development centres: care coordination for children with disabilities." *Child: Care, Health and Development,* 23(1), pp. 29-40.

ARA Consulting Group. (1992). *Final Report: Evaluability assessment of Ontario.* Toronto: ARA Consulting Group.

Bailey, D.B., S.A. Pasha and R.J. Simeonsson. (1991). "Professional skills, concerns, and perceived importance of work with families in early intervention." *Exceptional Children,* 58, pp. 156-165.

Bailey, J. and D. Bricker. (1984). "The efficacy of early intervention for severely handicapped infants and young children." *Topics in Early Childhood Special Education, 4*(3), pp. 30-51.

Bamberger, Michael. (1991). "The Importance of Community Participant." *Public Administration and Development,* 11, pp. 281-284.

Barrera, M. (1991). "The transactional model of early home intervention: Application with developmentally delayed children and their families." In Marfo, K. (Ed.). *Early intervention in transition: Current perspectives on programs for handicapped children.* New York, NY: Praeger.

Barrera, M. and P.L. Rosenbaum. (1986). "The transactional model of early home intervention." *Infant Mental Health Journal,* 7, pp. 112-131.

Baumgarten, M., et al. (1992). "The psychological and physical health of family members caring for an elderly person with dementia." *Journal of Clinical Epidemiology,* 45 (1), pp. 61-70.

Beckman, Paula J., Sandra Newcomb, Nancy Frank, Lynn Brown, Jennifer Stepanek and Deidre Barnwell. (1996). "Preparing Personnel to Work With Families." In *Preparing Personnel to Work With Infants and Young Children and Their Families: A Team Approach.* Diane Bricker and Anne Widerstrom eds. Baltimore: Paul H. Brookes, pp. 273-291.

Bickenbach, Jerome E. (1993). *Physical Disability and Social Policy.* Toronto: University of Toronto Press.

Bishop, Kathleen Kirk, Josie Woll and Polly Arango. (1993). *Family/Professional Collaboration for Children with Special Health Needs and Their Families.* Maternal and Child Health Bureau, U.S. Department of Health and Human Services.

Boschen, K. and N. Krane. (1992). "A history of independent living in Canada." *Canadian Journal of Rehabilitation,* 6 (2), pp. 79-88.

Braddock, D. and G. Fujiura. (1991). "Politics, public policy and the development of community mental retardation services in the United States." *American Journal of Mental Retardation,* 95 (4), pp. 369-387.

Bradley, Robert H., Howard P. Parette, Jr. and Alan VanBiervliet. (1995). "Families of Young Technology-Dependent Children and the Social Worker." *Social Work in Pediatrics,* 21 (1), pp. 23-37.

Bricker, Diane and Anne Widerstrom. (1996). *Preparing Personnel to Work with Infants and*

Young Children and Their Families: A Team Approach. Baltimore: Paul H. Brookes.

British Columbia Ministry of Social Services. (October 1995). *Individualized Funding and Service Brokerage Pilot*. Research, Evaluation and Statistics Branch, Policy, Planning and Research Division.

Broughton, B.K. and N. Lutner. (1995). "Chronic Childhood Illness: A Nursing Health-Promotion Model for Rehabilitation in the Community." *Rehabilitation Nursing*, 20, pp. 318- 322.

Brown, Roy I. (1994). "Quality of Life — Adults and Adolescents with Disabilities." *Exceptionality Education Canada*, 4 (1), pp. 1-11.

Brown, W., S.K. Thurman and L.F. Pearl. (Eds.). (1993). *Family-Centred early intervention with infants and toddlers: Innovative cross-disciplinary approaches*. Baltimore: Paul H. Brookes Publishing Co.

Brown, Ralph A. and Andrew Debicki. (1999). *The Wraparound Process: Strength-Based Practice*. Unpublished article.

Browne, N., A. Corbett, A. Gallant and E. Thompson. (1985). "Direct home service program: Service plan for a community-based developmental service." *Canadian Journal on Mental Retardation*, 35 (2), pp. 8-12.

Bruder, M.B. and T. Bologna. (1993). "Collaboration and service coordination for effective early intervention." In Brown, W., S.K. Thurman and L.F. Pearl. (Eds.). *Family-Centred early intervention with infants and toddlers: Innovative cross-disciplinary approaches*. Baltimore: Paul H. Brookes Publishing Co.

Brynelsen, D. and H. Cummings. (1987). *Infant development programs: Early intervention in delayed development*. In Denholm, C., R. Ferguson and A. Pence. (Eds.). *Professional child and youth care: The Canadian perspective*. Vancouver, B.C.: University of British Columbia Press.

Burns, T.J., et al. (1990). "Primary health care needs of persons with physical disabilities: What are the research and service priorities?" *Arch Physical Medical Rehabilitation*, 71, February, pp. 138-143.

Caledon Institute of Social Policy. (June 1996). *Sustainable Social Policy and Community Capital, Session Proceedings*, Summer Program of the Institute in Management and Community Development. Caledon Institute and the Canada Mortgage and Housing Corporation.

Caledon Institute of Social Policy. (June 1998). *Perspectives on Partnership*. Social Partnerships Project, Caledon Institute.

Camfield, P., et al., (1994). *Review of children's training centres*. Report commissioned by the Government of Nova Scotia.

Canada. Health and Welfare. (1993). *Pathway to integration: Final report, Mainstream 1992*. Report to Ministers of Social Services on the Federal/Provincial/Territorial Review of Services affecting Canadians with Disabilities.

Canada. Minister Responsible for the Status of Disabled Persons. (1987). *Obstacles: 1987 Report update*. Ottawa, Ontario: Minister of Supply and Services.

Canadian Association for Community Living. (1987). *Community living 2000: A time of change, a time of challenge*. North York, Ontario: Canadian Association for Community Living.

Canadian Association for Community Living. (1988). *Replacing institutions: A challenge to end segregation - A call to action to the Government of Canada*. North York, Ontario: Canadian Association for Community Living.

Canadian Association of Independent Living Centres. (1993). *A time for change: The time for choices. A proposal for improving the social security arrangements for Canadians with disabilities*. Ottawa: Canadian Association for Living Centres.

Canadian Institute of Child Health. (CICH). (1994). *The Health of Canada's Children: a CICH profile*. Ottawa: CICH.

Canadian Institute of Child Health. (CICH). (2000). *The Health of Canada's Children*. Third Edition, Ottawa: CICH.

Cassell, E.J. (1995). "Teaching the fundamentals of primary care." *The Milbank Quarterly*, 73, 3, pp. 373-405.

Center for Case Management. (1995). *Managing Outcomes through Collaborative Care. The Application of CareMapping and Case Management*. American Hospital Publishing Inc.

Chrichton, Anne and Lyn Jongbloed. (1998). *Disability and Social Policy in Canada*. Toronto: Captus.

Circles Network. (1995). *Circles of Support: Building Inclusive Communities*. Alison Wertheimer, Ed. Circles Network UK.

Clark v. Clark. (1982). 40 O.R. (2d) at 392 (Co. Ct.) per Matheson, J.

Cole, Audrey. (1991). "Guardianship: A blow against freedom." *entourage*, 6, 4, pp. 2-4.

Collins, J. (1992). *When the eagles fly: A report on resettlement of people with learning difficulties from long-stay institutions*. Wembley, Middlesex: Values into Action.

Comité des bénéficiares du Centre d'acceuil Pavillon Saint-Théophile c. Centre d'acceuil Pavillon Saint-Théophile. (1992). C.H.H.R., 16, p. 139.

Commission des droit de la personne c. Jean Coutu. (1995). Quebec, Montreal, 10 May per Sheehan, M.

Community Information Centre of Metropolitan Toronto. (1996). *The blue book directory of community services of Metropolitan Toronto*. Toronto, Ontario: The Community Information Centre of Metropolitan Toronto.

Conroy, J. and V. Bradley. (1985). *The Pennhurst longitudinal study: A combined report of five years of research and analysis*. Philadelphia: Temple University Developmental Disabilities Centre.

Cook, J. (1988). "Goffman's legacy: The elimination of the chronic mental patient's community; A review of selected literature." *Research in the Social of Health Care*, 7, pp. 249-281.

Coutts, J. (1996, January 26). "Ontario hopes competition will improve long-term care." *The Globe and Mail*, p. A7.

Crabtree, L. (1990). "Health care and women with disabilities." *Rehabilitation Digest*, Fall, pp. 3-7.

Craig, E.M. and R.B. McCarver. (1984). "Community placement and adjustment of deinstitutionalized clients: Issues and findings." In Ellis, N.R. and N.W. Bray. (Eds.). *International review of research in mental retardation*. New York: Academic Press Inc.

Criscione, T., T.A. Kastner, D. O'Brien and R. Nathanson. (1994). "Replication of a managed health care initiative for people with mental retardation living in the community." *Mental Retardation*, 25 (4), pp. 227-232.

Cummins, Robert A. and Christine Baxter. (1997). "The Influence of Disability and Service Delivery on Quality of Life Within Families." *International Journal of Practical Approaches to Disability*, 21 (3), pp.2-8.

DeLong, Lou Ann and Michael Boyer. (1991). "Bringing Them Home: Community Supports for the Medically Fragile Child." *Journal of Child and Youth Care*, 6 (1), pp. 37-42.

Dickey, Jo. (1991). "Discarded Relationships: Parents and the mechanisms of guardianship." *entourage*, 6, 4, pp. 6-8.

Dunst, C.J., C.M. Trivett, A.L. Starnes, D.W. Hamby and N.J. Gordon. (1993). *Building and evaluating family support initiatives*. Baltimore: Paul H. Brookes Publishing Co.

Dykstra, Art, Jr. (1995). *Outcome Management: Achieving Outcomes for People with Disabilities*. East Dundee: High Tide Press.

Emerson, E. (1985). "Evaluating the impact of deinstitutionalization on the lives of mentally retarded people." *American Journal of Mental Deficiency*, 90 (3), pp. 277-288.

Endicott, Orville. (1990). *The right of persons with intellectual handicaps to receive medical treatment*. North York, Ontario: The Canadian Association for Community Living.

Engel, G. (1989). "On the Vicissitudes of Health Appraisal." *Advances in Nursing*

Science, 7 (1), pp. 12-23.

Epp, Jake. (1986). Minister of National Health and Welfare. *Achieving health for all: A framework for health promotion*. Ottawa: Minister of Supply and Services Canada.

Falvey, Mary A., Marsha Forest, Jack Pearpoint and Richard L. Rosenberg. (1997). *All My Life's A Circle, Using the Tools: Circles, MAPS & PATHS*. Inclusion Press.

Foreman, Philip J. and Judith Neilands. (1991). "Parental perceptions of services to children with intellectual disability." *Australia and New Zealand Journal of Developmental Disabilities*, 17, 2, pp. 249-258.

Fudge, D. (1988). *Deinstitutionalization: A trade union perspective*. National Union of Provincial Employees.

Galambos, Diane. (1995). *Planning...to have a life: Individualized planning for quality of life*. North York: Sheridan College.

Galambos, Diane and Patti W. Whetstone. (1989). *Individual Program Planning*. Oakville, Ontario: Instructional and Human Resources

Development, Sheridan College of Applied Arts and Technology.

Gitta, Maria Z. and Dr. George Deagle. (1992a). "What family doctors want to know: Part 2, family physician survey." *University of Western Ontario, Clinical Bulletin of the Developmental Disabilities Program*, 3, 3, pp. 1-3.

Gitta, Maria Z. and Dr. George Deagle. (1992). "What family doctors want to know: Preliminary report of the developmental disabilities program, family physician survey." *University of Western Ontario, Clinical Bulletin of the Developmental Disabilities Program*, 3, 1, pp. 1-3.

Government of Canada. (1982). *The Charter of Rights and Freedoms: A guide for Canadians*. Ottawa, Ontario: Minister of Supply and Services Canada.

Griswold, K.S., M.E. Msall and R.E. Cooke. (1987). :A University-based health maintenance organization for persons with developmental disabilities: An editorial." *Mental Retardation*, 25, 4, pp. 223-225.

Haverstock, Shannon Lee. (1992). *Learning to Care for Chronically-Ill, Technology-Dependent Children: Mothers' Experiences of Skill Acquisition*. Unpublished master's dissertation, University of Toronto.

Hayden, Mary F. and Paris A. DePaepe. (1991). "Medical conditions, level of care needs, and health-related outcomes of persons with mental retardation: A review." *Journal of the Association of Persons with Severe Handicaps*, 16, 4, pp. 188-206.

Hayden, Mary F. and Brian H. Abery. (Eds.). (1994). *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities*. Baltimore: Paul H. Brookes.

Hayden, Mary F. and Paris A. DePaepe. (1994). "Waiting for community services: The impact on persons with mental retardation and other developmental disabilities." In Hayden, M.F. and B.H. Abery. (Eds). *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities*. Baltimore: Paul H. Brookes.

Hays, Virginia, Marcus Hollander, Elsie Tan and J. Eden Cloutier. (1997). *Services for Children with Special Needs in Canada*. A report prepared for the Canadian Association for Community Care and Health Canada. Canadian Policy Research Networks Inc.

Hazel, R., P.A. Barber, S. Roberts, S.K. Behr, E. Helmsetter and D. Guess. (1988). *A community approach to an integrated service system for children with special needs*. Baltimore: Paul H. Brookes.

Health Canada. (1997). *Moving Along, Growing Strong: The Final Report of the Atlantic Community Action Program for Children (CAPC) Regional Evaluation*, prepared for the Health Promotion and Programs Branch, Atlantic Region.

Heinlein, K. and J. Fortune. (1995). "Who stays, Who goes? Downsizing the institution in America's most rural state." *Research in Developmental Disabilities*, 16 (3), pp. 165-177.

Heller, T. and D. Braddock. (1985). *Institutional closure: A study of resident impact*. Evaluation and Public Policy Program, University of Illinois at Chicago. Institute for the Study of Developmental Disabilities, Public Policy Monograph #19.

Herbert, Carol and John Milsum. (1990). *Measuring health: The documentation and evaluation of measurement procedures currently used to measure well-being*. Vancouver: University of British Columbia, Institute of Health Promotion.

Herr, Stanley and Barbara Hopkins. (1994). "Health Care: Decision making for persons with disabilities." *The Journal of the American Medical Association*, 271, p. 13.

Hill, B.K., K.C. Lakin, R.H. Bruininks, A.N. Amado, D.J. Anderson and J. Copher. (1989). *Living in the community: A comparative study of foster homes and small group homes for people with mental retardation. (Report No. 29)*. Minneapolis, MN: University of Minnesota, Centre for Residential and Community Services.

Hingsburger, Dave. (1987). "In a strange bed." *The Canadian Nurse*, August, pp. 21-22.

Hochstadt, Neil J. and Diane M. Yost. (Eds.). (1991). *The medically complex child: The transition to home care*. Chur, Switzerland: Harwood Academic Publishers.

Holburn, C. (1990). Rules: The new institutions. *Mental Retardation*, 28 (2), pp. 89-94.

Human Rights Research and Education Centre. (1990). *Human rights in Canada: Into the 1990s and beyond*. Ottawa, Ontario: University of Ottawa.

Isaacs, Barry, Stephanie Percival, Brydon Gombay and Nitza Perlman. (1994). "A Social Context for Understanding Quality of Life." *Journal on Developmental Disabilities*, 3 (2), pp. 45-58

Jaudes, Paula Kienberger. (1991). "The medical care of children with complex home health care needs: An overview for caretakers." In Hochstadt, N.J. and D.M. Yost. (Eds.) *The medically complex child: The transition to home care*. Chur, Switzerland: Harwood Academic Publishers.

Joyce, Kathleen, Mark Singer and Richaard Isralowitz. (1983). "Impact of Respite Care on Parents' Perceptions of Quality of Life." *Mental Retardation*, August, pp. 153-155

Kappel, B., E. Burke, J. Cathrope, E. Coish, G. Des Lauriers and L. Wray. (1983). *Futures of quality: A report on the development of community living arrangements for persons with mental handicaps in the Waterford Psychiatric Hospital system and the implications for all citizens with mental handicaps in Newfoundland and Labrador*. Downsview, Ontario: National Institute on Mental Retardation.

Kirk, S. (1997). "Families' experiences of caring at home for a techology-dependent child: a review of the literature." *Child: Care, Health and Development*, 24 (2), pp. 101-114.

Knapp, M., P. Cambridge, C. Thomason, J. Beecham, C. Allen and R. Darton. (1992). *Care in the community: Challenge and demonstration*. Hants, U.K. and Brookfield, VT: Ashgate Publishing.

Kohrman, Arthur F. (1991). "Medical technology: Implications for health and social service providers." In Hochstadt, N.J. and D.M. Yost. (Eds.). *The medically complex child: The transition to home care*. Chur, Switzerland: Harwood Academic Publishers.

Lakin, K. Charlie, Sheryl A. Larson and Robert Prouty. (1994). "Assessment and enhancement of quality services for persons with mental retardation and other developmental disabilities." In Hayden, M.F. and B.H. Abery. (Eds). *Challenges for a service system in transition: Ensuring quality community experiences for persons with developmental disabilities*. Baltimore: Paul H. Brookes.

Lightman, E. (1992). *A community of interests: The report of the Commission of Inquiry into Unregulated Residential Accommodation*. Toronto, Ontario: Queen's Printer.

Lord, John and Cheryl Hearn. (1987). *Return to the community: The process of closing an institution*. Kitchener, Ontario: Centre for Research and Education in Human Services.

Lynch, Evelyn C. and Nancy Herrud Staloch. (1988). "Parental perceptions of physicians' communication and informing process." *Mental Retardation*, 26, 2, pp. 77-81.

MARC (1995). *Opportunities for Collaboration: between the mental health and developmental service sectors*. Report of the Mental Health Committee. Toronto: MARC.

Marfo, K. (Ed.). (1991). *Early intervention in transition: Current perspectives on programs for handicapped children*. New York, NY: Praeger.

McCallum, S. Dulcie. (1991). "Guardianship: Beware the triggering events." *entourage*, 6, 4, pp. 8-10.

McConachie, Helen. (1997). "Editorial: Organization of child disability services." *Child: Care, Health and Development*, 23 (1), pp. 3-9.

McGowan, Karen Green and I.E. McGowan. (1994). *Assessing health risk in developmental disabilities*. Peachtree City, GA: McGowan Consultants.

McKeever, Patricia T. (1981). "Fathering the Chronically Ill Child." *American Journal of Maternal Child Nursing*, March/April, pp. 124-128.

Mendelson, M. (1994). "Well-being and new economic realities." *entourage*, 8 (2), pp. 3-4.

Metropolitan Toronto District Health Council (MTDHC). (1995). *It's my choice: Strategic framework for services for individuals with physical disabilities in Metropolitan Toronto*. Toronto, Ontario: Work Group on Services for People with Physical Disabilities, Metropolitan Toronto District Health Council.

Metropolitan Toronto District Health Council. (1997). *A Strategic Plan For Children with Long Term Care Needs in Metro Toronto*. Final Report. Toronto, ON: Metropolitan Toronto District Health Council.

Meyers, Allan R., et al. (1988). "Epidemiology of medical care utilization by severely disabled independently-living adults." *Journal of Clinical Epidemiology*, 41, 2, pp. 163-172.

Minihan, Paula M., Deborah H. Dean and Charles M. Lyons. (1993). "Managing the care of patients with mental retardation: A survey of

physicians." *Mental Retardation*, 31, 4, pp. 239- 246.

Ministry of Community and Social Services. (April 1997). *Making Services Work for People: A new framework for children and for people with developmental disabilities*. Ontario: Queen's Printer.

Mittler, Peter and Helle Mittler. (Eds.). (1994). *Innovations in Family Support for People with Learning Disabilities*. The Brothers of Charity, Lisieux Hall.

Morrissey, J.P., M. Calloway, W.T. Bartko, M.S. Ridgely, H.H. Goldman and R.I. Paulson. (1994). "Local mental health authorities and service system change: Evidence from the Robert Wood Johnson program on chronic mental illness." *The Milbank Quarterly*, 72, 1, pp. 49-80.

National Forum on Health. (1995). *The Public and private financing of Canada's health system*. Ottawa: National Forum on Health.

New Brunswick. Department of Health and Community Services (DHCS). (1985). *Action plan for the disabled of New Brunswick*. Saint John, New Brunswick: DHCS.

Nozick, Marcia. (1992). *No Place Like Home: Building Sustainable Communities*. Canadian Council on Social Development.

Nursey, A.D., J.R. Rohde and R.D.T. Farmer. (1990). "A study of doctors' and parents' attitudes to people with mental handicaps." *Journal of Mental Deficiency Research*, 34, pp. 143- 155.

Ontario College of Family Physicians (OCFP). (1995). *Bringing the pieces together. Planning for the future of health care: A strategy for primary health care planning*. Toronto: Ontario College of Family Physicians.

Ontario. Ministry of Community and Social Services. (1987). *Challenges and opportunities: Community living for people with developmental handicaps*. Toronto, Ontario: Queen's Printer for Ontario.

Ontario. Ministry of Community and Social Services (1997). *Making Services Work for People. A new framework for children and for people with developmental disabilities*. Toronto, Ontario: Queen's Printer for Ontario.

Ontario. Ministry of Health, Ministry of Community and Social Services and Ministry of Citizenship. (1993b). *Partnerships in long-term care. A new way to plan, manage and deliver services and community support: Guidelines for the establishment of multi-service agencies*. Toronto, Ontario: Queen's Printer for Ontario.

O'Brien, J. and H. Lovett. (1993). *Finding a way toward everyday lives: The contribution of person-centered planning*. Harrisburg: Pennsylvania Office of Mental Retardation.

Pante, Michelle. (June 18-19, 1996). "Social Partnerships, Sustainable Social Policy and Community Development." In *Sustainable Social Policy and Community Capital, Session Proceedings of the Summer Program in Management and Community Development*, Concordia University, Caledon Institute and CMHC, pp. 25-39

Patterson, E. (1996). "Nursing children with disabilities; a conceptual framework for organizing services." *Australian Journal of Advanced Nursing*, 13 (3), pp. 32-9.

Percy-Smith, Janie and Ian Sanderson. (1992). *Understanding local needs*. London, U.K.: Institute for Public Policy Research.

Peters, Y. (1991). "Focus on a human rights organization: The Canadian Disability Rights Council." *entourage*, 6 (2), pp. 11, 18.

Petr, C.G., B. Murdock and R. Chapin. (1995). "Home care for children dependent on medical technology: The family perspective." *Social Work in Health Care*, 21, pp. 5-22.

Rachlis, Michael and Carol Kushner. (1994). *Strong medicine: How to save Canada's health care system*. Toronto: Harper Collins.

Racino, J. (1993). "Opening the doors: The state role in housing and support." In Racino, J., P. Walker, S. O'Connor and S. Taylor. (Eds.). *Housing, support and community: Choices and strategies for adults with disabilities*. Vol 2, The Community Participation Series. Baltimore, MD.: Paul H. Brookes.

Rawls, John. (1971). *A theory of justice*. Cambridge, Mass: Harvard University Press.

Richler, Diane. (1991). "Emerging Realities: The case for community living - the case against segregation." *Abilities*, 7, pp. 19-21.

Roeher Institute. (1996a). *Building bridges*. North York, Ontario: The Roeher Institute.

Roeher Institute. (1994). *The Canadian disability*

resource program: Offsetting costs of disability and assuring access to disability-related supports. Toronto: Author.

Roeher Institute. (1994b). *The Canadian disability resource program: Offsetting costs of disability and assuring access to disability-related supports.* North York, Ontario: The Roeher Institute.

Roeher Institute. (1994a). *Coming home, Staying Home. Legal Research: Supported decision making and the restriction of guardianship.* North York, Ontario: The Roeher Institute.

Roeher Institute. (1996). *Disability, Community and Society: Exploring the Links.* Toronto: The Roeher Institute.

Roeher Institute. (1994). *Disability is not measles: New research paradigms in disability.* Toronto: Author.

Roeher Institute. (April 1997). *Evaluations of the CHOICES Project, Final Report.* Toronto: The Roeher Institute.

Roeher Institute. (March 1997). *Family-Driven Networks of Support, Evaluation Report.* Submitted to Massachusetts Families Organizing for Change. Toronto: The Roeher Institute.

Roeher Institute. (1998). *Health Planning Innovations Project: Background Report - Developing a Model for Health Planning for People with Disabilities Including Those With Complex Medical Needs.* Toronto: Author.

Roeher Institute. (1999). *Labour Force Inclusion of Parents Caring for Children with Disabilities.* Toronto: The Roeher Institute.

Roeher Institute. (May 1998). *National Evaluation of NSIPD Deinstutionalization Initiative, Final Report.* Toronto: The Roeher Institute.

Roeher Institute. (1993b). *Nothing personal: The need for personal supports in Canada.* North York, Ontario: The Roeher Institute.

Roeher Institute. (1991). *The power to choose: An examination of service brokerage and individualized funding as implemented by the Community Living Society.* North York, Ontario: Roeher Institute.

Roeher Institute. (1995). *Research issues in evaluating deinstitutionalization: A review of the Literature.* North York, Ontario: The Roeher Institute.

Roeher Institute. (1993). *Social well-being: A paradigm for reform.* Toronto: Author.

Saskatchewan. Ministry of Health. (1990). *Future directions for health care in Saskatchewan.* Regina, Saskatchewan: Government of Saskatchewan.

Schwartz, David B. (1992). *Crossing the River: Creating a Conceptual Revolution in Community & Disability.* Brookline Books.

Shelton, Terri L. and Jennifer Smith Stepanek. (1995). "Excerpts From Family-Centered Care For Children Needing Specialized Health and Development Services." *Pediatric Nursing,* 21 (4), pp. 362-364.

Simeonsson, R.H., R. Edmondson, T. Smith., S. Carnahan and J.E. Bucy. (1995). "Family involvement in multidisciplinary team evaluation: professional and parent perspectives." *Child: Care, Health & Development,* 21 (3), pp. 199-214; discussion, pp. 214-15.

Simeonsson, N.W. and M.S. Lorimer. (1995). "Transition planning in early intervention: nurse practitioner implications." *Journal of Pediatric Health Care,* 9 (4), pp. 172-7.

Simmons, H. (1982). *From asylum to welfare.* Downsview, Ontario: National Institute on Mental Retardation.

Singer, George H.S., Laurie E. Powers and Ardis L. Olson. (1996). *Redefining Family Support: Innovations in Public-Private Partnerships.* Baltimore: Paul H. Brookes.

Sloper, Patricia and Stephen Turner. (1992). "Service needs of families of children with severe physical disability." *Child: Care, health and development,* 18, pp. 259-282.

St. Elizabeth Health Care. (1996). *Tradition of Excellence.* Pamphlet. Don Mills, Ontario: St. Elizabeth Health Care, Corporate Office.

Taylor, A.R., S.R. Asher and G.A. Williams. (1987). "The social adaptation of mainstreamed mildly retarded children." *Child Development,* 58, pp. 1321-1334.

Taylor, Steven J., Robert Bogdan and Julie Ann Racino. (Eds.). (1991). *Life in the Community: Case Studies of Organizations Supporting People with Disabilities.* Baltimore: Paul H. Brookes.

Thames Valley District Health Council. (1995). *A Model for the Coordination and Reconfiguration of Services for Children and Youth with High/Complex Care Requirements.* Thames Valley District Health Council.

Thompson, R.J. and K.E. Gustafson. (1996). *Adaption to Chronic Childhood Illness*. Washington, D.C.: American Psychological Association.

Torjman, Sherri. (October 1998). *Strategies for a Caring Society*. The Caledon Institute of Social Policy.

University of Western Ontario. (1995). *Summary of findings from focus group with physicians*. Developmental Disabilities Program.

Valentine, F. (1994). *The Canadian independent living movement: An historical overview*. Ottawa: Canadian Association of Independent Living Centres.

VanDenBerg, John and E. Mary Grealish. (1998). *The Wraparound Process: Training Manual*. Pittsburgh: The Community Partnerships Group and Hamilton: Lynwood Hall Child and Family Centre.

Wegner, E. (1990). "Deinstitutionalization and community-based care for the chronically mentally ill." *Research in Community and Mental Health*, 6, pp. 295-324.

Wharton, R.H., K.R. Levine, S. Buka and L. Emanuel. (1996). "Advance care planning for children with special health care needs: a survey of parental attitudes." *Pediatrics*, 97 (5), pp. 682-7.

White, B. (1992-93). "Labour and community living: New coalitions for change." *entourage*, 7, 4, pp. 3-5.

Whittaker, A., S. Gardner and J. Kershaw. (1991). *Service evaluation by people with learning difficulties*. Based on the People First Report: An evaluation of services in London Borough of Hillingdon. London: King's Fund Centre.

Wilgosh, L. and S. Chomicki. (1991). "Parents' perceptions of health care for children with disabilities." *Canadian Journal of Special Education*, 7, 1, pp. 67-73.

Woronko, Stan, Marilyn Dolmage, Elizabeth Rose and Myroslaw Tataryn. (July 1994). *Families Do It Better: better supports for special needs and better deal for taxpayers*. Special-Services-at-Home, Family Alliance, Family Support Institute of Ontario.

Worth, P. (1988). "A self-advocates perspective." In Rioux, M. (Ed.). *The language of pain: Perspectives on behaviour management*. North York, Ontario: The Roeher Institute.

Wright, Lisa. (November 1, 1994). "Nurses protest long-term care legislation." *The Toronto Star*, pp. N.A.

Yerbury, Margaret. (1997). "Issues in multidisciplinary teamwork for children with disabilities." *Child: Care, Health and Development*, 24 (2), pp. 77-86.

Zirpoli, T. and C. Wieck. (1989). "Economic and political factors affecting deinstitutionalization: One state's analysis." *Journal of Special Education*, 23 (2), pp. 201-211.

APPENDIX A
DEMOGRAPHICS: PEOPLE WITH COMPLEX MEDICAL NEEDS

Non-institutionalized adults with disabilities

Canadian statistical sources provide only limited information about people with disabilities and complex medical needs. Depending on the source used, a variety of indicators of "complex medical needs" can be used. Based on the Health and Activity Limitation Survey, 1991, we know the following about the 3.5 million adults with disabilities living in households (i.e., not in health-related institutions):

- 297,000 people use specialized aids or equipment to assist with respiration, such as respirators, ventilators, TENS devices, or oxygen
- 23,000 use emergency call systems, and 23,000 need such systems but do not have them
- 286,000 need help from other people for personal care (i.e., washing, grooming, dressing or eating)
- 157,000 people need assistance moving about at home because of their condition
- 2.2 million use prescription or non-prescription drugs on a regular basis, i.e., at least once a week — of these people, 2 million use prescription medications on a daily basis
- 866,000 had expenses for medications because of their condition that were not reimbursed by any private or public plan in 1991
- 484,000 claimed the Medical Expenses Tax Credit for items and services needed because of disability
- 927,000 people live with what they characterize as a moderate level of pain, and another 570,000 live with severe pain
- 163,000 encountered barriers to receiving health-related services in 1991 (dentist, nurse, chiropractor, psychologist, social worker, counsellor, mental health worker, physiotherapist, occupational therapist or speech and language pathologist, family doctor/general practitioner, medical specialist such as a heart specialist). The leading barriers given were: location, cost, inaccessible facilities or services, inadequate transportation, and needing help from someone else
- 107,000 had non-reimbursed expenses for disposable items needed because of their condition or health problem, 235,000 for specialized clothing, aids, medical supplies, and equipment, and 223,000 for health and medical services not covered by any insurance plan, such as additional hospital or physician fees
- 1.2 million people want to be more physically active but consider themselves physically unable to do more activities

Source:

Statistics Canada. (1994). *Selected Characteristics of Adults with Disabilities Residing in Households, 1991 Health and Activity Limita-*

tion Survey. (Table 3). Ottawa: Minister of Industry, Science and Technology.

Unpublished research conducted by The Roeher Institute using Statistics Canada's 1996-97 National Population Health Survey found the following information about people aged 15 and older who have "activity restrictions" (disabilities):

- 992,000 rate their general health as only "fair" and another 446,000 rate their health as "poor"
- Among those rating their health as only fair or poor, 25% have musculoskeletal conditions, 14% have conditions affecting the central nervous system or senses, 13% have arthritis, 12% have various conditions of the heart, 9% have diseases of the respiratory system, 4% have circulatory diseases, and 25% have various other conditions
- 250,000 of these people felt that health care services were needed in the 12 months prior to the survey but did not receive the services needed. Leading reasons given as to why such services were not obtained included: felt service would be inadequate (52,000), cost (50,000, waiting time would be too long (50,000), service not available when required (37,000) and service not available in the geographic area (30,000).

Non-institutionalized children with disabilities

Research based on the 1996-97 National Population Health Survey (NPHS) has found the following:

- There are nearly 565,000 children and youth between birth and 19 years of age (living in households) who had disabilities when the survey was conducted — 7.7% of all children living in households.
- The general health status of children with disabilities in the 4 to 14 years of age group is excellent or very good for only 58%, compared with 87% among other children this age.

Source:

Canadian Institute of Child Health. (2000). *The Health of Canada's Children, Third Edition*. Ottawa: CICH.

Based on earlier information the following is known:

- Among children with disabilities, 15% (more than 80,000 children) have a moderate or severe level of disability.
- More than 200,000 children from birth to 15 years have long-term health problems or chronic conditions aside from asthma, allergies, and bronchitis
- More than 160,000 are limited or prevented from participating in school, play, or other typical activities because of long-term conditions
- Nearly 20,000 had non-reimbursed expenses for health and medical services in 1991, and nearly 80,000 had non-reimbursed expenses for prescription and non-prescription drugs taken regularly because of a long-term condition (Statistics Canada, 1994: Table 5).

Sources:

Canadian Institute of Child Health. (1994). *The Health of Canada's Children, A CICH Profile, Second Edition*. (Table 3). Ottawa: CICH; Statistics Canada. (1994). *Selected Characteristics of Adults with Disabilities Residing in Households, 1991 Health and Activity Limitation Survey*. (Table 5). Ottawa: Minister of Industry, Science and Technology.

Adults with disabilities living in health-related institutions

- In 1991, 262,000 adults with disabilities lived in health-related institutions and residences for seniors. Some 11,000 of these people were aged 15 to 34 years. The number of residents aged 35 and over increased from 228,000 to 251,000 from 1986 to 1991. Two out of three institutional residents were women.

Source:

Statistics Canada. (1994). *Selected Characteristics of Adults with Disabilities Residing in Households, 1991 Health and Activity Limitation Survey*. Ottawa: Minister of Industry, Science and Technology, p. xxvi.

APPENDIX B
PARTICIPANTS IN THE FOCUS GROUPS AND THE QUESTIONS DISCUSSED

Participants in the Focus Groups

The researchers would like to acknowledge the participation of all the individuals who provided their insights into health planning for the purposes of this report. The following individuals consented to having their names presented in the report for public acknowledgement.

Focus group of Families:

Jim Dolmage
Matt Dolmage
Felicia Jervis
Jim Johnston
Elgi Johnston

Focus group of Paediatricians:

Dr. Katy Driver
Dr. Anthony E. Ford-Jones
Dr. H. Anne Richards
Dr. Jonathan B. Tolkin

Focus group of Family Physicians:

Dr. Paul Colford
Dr. Fred Tudiver
Dr. Karen E. Jones
Dr. Kingsley Watts
Dr. Itamar Tamari
Dr. Dave Wheler

Focus group of Health Care Coordinators:

Jean Anthony, RN
P. Ruth Quinn, RN
Norma Brown, RN
Fern Quint, RN
Dorothy Kristensen, RN
Sandy Stemp
Patricia E. LeBlanc, RN
Therese Verkuyl, RN
Pat McCracken, RN

HEALTH PLANNING INNOVATIONS PROJECT

Focus Groups:

MEDICAL SPECIALISTS/PAEDIATRICIANS

February 23, 1995

Questions for Discussion

1. Training and Education

- What exposure do physicians have to knowledge about individuals with developmental disabilities while in medical school, during their residency, or in continuing medical education?
- What are the opportunities for exploring issues (e.g. diagnostic, clinical and social) concerning individuals with disabilities within the core curriculum and through continuing education?

2. Service Delivery

- In your opinion, what are some of the key issues and concerns of families in obtaining health care services and supports for children and elderly family members with an intellectual disability?
- How do the health care needs of individuals with life-long disabilities differ from those of individuals with age-acquired disabilities? Is the point in time at which the disability is acquired (i.e. at birth; childhood; adult; senior) crucial to the type of health services required, and how they are then delivered?
- How does the network of care (via formal systems and parents, siblings, and family) change as the individual with an intellectual disability ages?
- What issues do medical professionals encounter in:
  - i. handling common medical problems of persons with disabilities?
  - ii. responding to the functional limitations of persons with disabilities?
  - iii. having a person with a disability in the waiting room?
  - iv. ensuring accessibility to your office (physical accessibility, communication barriers) for people with disabilities.
- What are some of the communication gaps that exist between the systems of clinical care and social services?
- What are the kinds of health care and information networks that physicians are able to access currently? What kinds of referrals do they tend to provide to their patients?

3. Attitudes and Awareness

- What is your perception of the expectations of patients with intellectual disabilities and their families and advocates from the health care system?
- To what extent are physicians aware of the support groups for parents who have children with intellectual disabilities and do they refer parents to such groups?
- To what extent are physicians aware of support groups for persons who care for aging family members with or without intellectual disabilities, and do they refer their patients to such groups?
- Do you have any concerns about how physicians tend to view individuals with disabilities (i.e. disability as a disease; as curable)?

4. Funding and Incentives

- What incentives are currently in place for physicians to play a role in health promotion of persons with disabilities, and in the coordination of needed services and supports?
- What are the kinds of alternative funding plans and planning frameworks that could allow for better health care coordination?

HEALTH PLANNING INNOVATIONS PROJECT

Focus Groups:

GENERAL PRACTITIONERS

March 9, 1995

Questions for Discussion

1. Training and Education

- What exposure do physicians have to knowledge about individuals with developmental disabilities while in medical school, during their residency, or in continuing medical education?

- What are the opportunities for exploring issues (e.g. diagnostic, clinical and social) concerning individuals with disabilities within the core curriculum and through continuing education?

2. *Service Delivery*

- In your opinion, what are some of the key issues and concerns of families in obtaining health care services and supports for children and elderly family members with an intellectual disability?
- How do the health care needs of individuals with life-long disabilities differ from those of individuals with age-acquired disabilities? Is the point in time at which the disability is acquired (i.e. at birth; childhood; adult; senior) crucial to the type of health services required, and how they are then delivered?
- How does the network of care (via formal systems and parents, siblings, and family) change as the individual with an intellectual disability ages?
- What issues do medical professionals encounter in:
  - i. handling common medical problems of persons with disabilities?
  - ii. responding to the functional limitations of persons with disabilities?
  - iii. having a person with a disability in the waiting room?
  - iv. ensuring accessibility to your office (physical accessibility, communication barriers) for people with disabilities.
- What are some of the communication gaps that exist between the systems of clinical care and social services?
- What are the kinds of health care and information networks that physicians are able to access currently? What kinds of referrals do they tend to provide to their patients?

3. *Attitudes and Awareness*

- What is your perception of the expectations of patients with intellectual disabilities and their families and advocates from the health care system?
- To what extent are physicians aware of the support groups for parents who have children with intellectual disabilities and do they refer parents to such groups?
- To what extent are physicians aware of support groups for persons who care for aging family members with or without intellectual disabilities, and do they refer their patients to such groups?
- Do you have any concerns about how physicians tend to view individuals with disabilities (i.e. disability as a disease; as curable)?

4. *Funding and Incentives*

- What incentives are currently in place for physicians to play a role in health promotion of persons with disabilities, and in the coordination of needed services and supports?
- What are the kinds of alternative funding plans and planning frameworks that could allow for better health care coordination?

HEALTH PLANNING INNOVATIONS PROJECT

Focus Groups:

HEALTH CARE COORDINATORS AND SERVICE PROVIDERS

February 22, 1995

Questions for Discussion

- From your perspective, what is the experience of persons with intellectual disabili-

ties in gaining access to health care?

- In your opinion, do the health care needs of individuals with life-long disabilities differ from those of individuals with age-acquired disabilities? Is the point at which the disability is acquired (i.e. birth, childhood, adult, senior years) crucial to the type of health services required, and to how they are delivered?
- What are the kinds of services that individuals with disabilities currently access at the community level? How are individuals with disabilities made aware of the existence of such services (i.e. referrals, media, social services)?
- What are some of the communication gaps that you experience between health care and social service systems?
- In your opinion, what are some of the key issues and concerns of families in obtaining health care services and supports for children or elderly family members with intellectual disabilities? What factors are at the root of these issues?
- How do physicians and other health care specialists that you deal with tend to view individuals with disabilities? (i.e. disability as a disease; as curable)
- What issues concerning people with intellectual disabilities do you feel would be useful for doctors and service providers to address in their training?
- What incentives are currently in place to enable coordination among health care and social services? What are the disincentives to coordination?
- What alternative funding plans and planning frameworks would allow for better health care coordination and linkage among health and social services?
- What impact might funding changes under long-term care have on the coordination of health and social services?

HEALTH PLANNING INNOVATIONS PROJECT

Focus Group:

FAMILIES

May 23, 1995

Questions for Discussion

- From your perspective, what is the experience of persons with disabilities and their families in gaining access to health care?
- What are the kinds of health care services that individuals with disabilities currently access at the community level? How do you find out about the existence of these services?
- How do physicians and other health care specialists that you deal with tend to view individuals with disabilities? (i.e. disability as a disease; as curable).
- What are some of the gaps that you experience between health care and social service systems?
- In your opinion, what are some of the key issues and concerns of families in obtaining health care services and supports for children or older family members with intellectual disabilities? What do you think are some of the causes of these issues?
- What incentives are currently in place to enable coordination among health care and social services? What are the disincentives to coordination? How could these disincentives be dealt with?
- What issues concerning people with disabilities and their families, do you feel would be useful to doctors and service providers to address in their training?

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